Advanced Respiratory Disease and Palliative Care

Summary Report

St. James’s Hospital
Our Lady’s Hospice & Care Services, Harold’s Cross
Liberties Primary Care Team
Irish Hospice Foundation
Summary Report of the Action Research Project on Developing Palliative Care Responses for People with Advanced Respiratory Disease

January 2010-June 2012

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Photograph on front courtesy of Julien Behal, Press Association, October 2012

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INTRODUCTION

Context

Since its establishment in 2002, the Respiratory Assessment Unit (RAU) in St. James’s Hospital, Dublin increasingly recognised the need for palliative care for their patients with advanced respiratory disease. With the timely publication of the Palliative Care for All Report (2008) came the recognition that the principles of palliative care need to be embedded within all disease frameworks and no longer confined to malignant disease.

Three collaborative action research projects were subsequently established by the Irish Hospice Foundation to determine models of care that would embed a palliative approach to people with dementia, heart failure and the focus of this project – advanced respiratory disease. A steering group was established representing St. James’s Hospital, Our Lady’s Hospice and Home Care Services and Liberties Primary Care Team (see Figure 1 below and more details on page 2). A part-time research project officer was appointed for two years and was based in St. James’s Hospital, reporting to this committee. The aim of this project was to devise, implement and evaluate appropriate palliative care responses for people with advanced respiratory disease within an Irish health care context.

The purpose of this summary report is to highlight the respiratory palliative care interventions from this project for their use by other respiratory and palliative care teams.

Figure 1. From left to right; Rory O'Donnell, Patricia White, Marie Lynch, Bettina Korn, Cathriona Corcoran, Stephen Shelly and Kaye Kealy
Background

The term advanced respiratory disease in this report refers to advanced non-malignant disease, in particular that of chronic obstructive pulmonary disease (COPD hereafter). COPD is characterised by ‘progressive airflow limitation that is not fully reversible and is associated with an abnormal airway inflammatory response to noxious particles or gases’. It is not one single disease but an umbrella term and encompasses previously used terms such as ‘emphysema’ and ‘chronic bronchitis’. COPD is best understood as systemic disease as it effects more than the respiratory system, with reported co-morbidities such as heart disease, diabetes, osteoporosis, malnutrition, anxiety and depression. On an international scale, the World Health Organisation (WHO) predicts that by 2030, COPD will be the third leading cause of death in the world. In Ireland, diseases of the respiratory system are the cause of one in five deaths – this is almost double the EU average.

Although the last decade has seen a growing recognition of the importance of extending palliative care for all life-limiting illnesses, palliative care for people with advanced respiratory disease is still an under recognised topic of research.

Burden of COPD

One way of examining the burden of the disease is through comparisons with lung cancer. It is now well documented that not only do patients with COPD have a higher disease burden, they also have significantly less access to resources and support to ease this burden compared to those with lung cancer. Those with COPD have worse health related quality of life, most of their symptoms are more prevalent, they have lower functional level for longer, are more likely to be admitted to an acute hospital or ICU, are less likely to know prognosis is poor and less likely to receive medication to control symptoms. Furthermore, patients with COPD have the same wish to focus on comfort, not prolonging life and the same wish as lung cancer patients not to be intubated or receive CPR.

Referral criteria

Many of the barriers to providing specialist palliative care derive from the unpredictable disease trajectory of respiratory disease and currently there is no guiding, evidence based palliative care referral criteria for people with advanced respiratory disease. Analysis of the literature identified nine relevant studies/policies on end of life care for respiratory patients, which identified the following four consistently used common referral criteria for specialist palliative care:

1) FEV < 30%,
2) Increased hospitalisations,
3) Poor functional status
4) On long-term oxygen therapy
To address the uncertainty of the COPD illness trajectory, there is a need to use a wide range of criteria for referral. One way of doing this is to look beyond physiological markers and a novel approach which is used in palliative care is the use of the surprise question. The health care professional asks themselves ‘Would I be surprised if this person died within the next 12 months?’ How this question is answered could determine the approach to the management of the patient. The surprise question has significant prognostic power with advanced cancer and dialysis patients\(^{18}\). However, it should not be used in isolation but as part of a holistic assessment of patients’ needs.

In the absence of evidence for palliative care for people with end-stage COPD, Murray et al.\(^{16}\) advocate the use of general palliative care principles such as; providing information to patients, controlling of symptoms, ensuring continuity of care and proactive management and provide useful questions for opening a discussion on end-of-life care (Table 1).

**Table 1. Questions for opening discussions with patients on end-of-life (Murray et al., 2006)**

- If things got worse, where would you like to be cared for?
- What’s the most important issue in your life right now?
- What helps you keep going?
- What is your greatest problem?
- You seem cheerful at present but do you ever feel down?

As identified in the literature, it is now time for a new model of care. What is needed is a fundamental change, a move away from prognosis-based care\(^8\) and the prognostic paralysis that dominates end stage palliative care\(^{16}\). By doing this it will empower both the patient and the family, e.g. by dispelling fears about death and realising the need to accept the uncertain prognosis\(^{12}\). It will also allow for practical planning e.g. preferred place of care, ventilation choices, resuscitation wishes and living wills.

**Aim of Project**

To devise, implement and evaluate appropriate palliative care responses for people with advanced respiratory disease within an Irish health care context.
METHODOLOGY

An action research methodology was chosen as it is particularly suited to small scale projects which strive to bring about change which is identified locally but applicable in a wider context. The partnership and reflective nature of action research ensured that all those involved in the care of patients with respiratory disease were collectively involved in the development of the project. This was a timely design as

‘action research is beginning to be utilised within palliative care research to address questions concerned with practice and organisational change’

(Froggatt & Hockley, 2011)\(^1\).  

There are two core elements to action research.

1. The first is that it is a cyclical process. Coghlan & Brannick (2010)\(^2\) describe the steps in the action research cycle as; pre-step; where the context and purpose are defined followed by constructing, planning action, taking action and finally evaluation (see Figure 2 below). However, action research happens in real life settings and so does not always follow such a cyclical route, there can be cycles that do not develop or spiral into other cycles.

2. The second core element in action research is the active involvement of stakeholders. It is the people living/working in the situation who are the experts, they have invaluable insights and are well qualified to be involved in the research. Because action research is about the process not just the products of research – it should directly benefit the participants. In this research the stakeholders go beyond those on the steering committee and included:

- Patients
- Family members/carers
- Respiratory nurses
- Nurses on respiratory ward
- Physiotherapists
- Respiratory consultants
- Palliative care nurses
- Palliative care consultants
- Community SPC* teams
- Primary care teams

\(^*\)SPC = Specialist Palliative Care

Figure 2. Example of an action cycle
INTERVENTIONS AND ACTION CYCLES

The image of a tree was used to capture the variety of actions that were part of this project (see Figure 3 below). The key interventions are discussed here.

1. Building Collaboration and Communication

This proved to be the key to developing palliative care interventions across teams and project sites and involved several approaches

- **Meetings**: there were regular meetings with the Steering Group every two months but due to peoples busy clinical workload, finding a suitable time for everyone to attend proved a constant challenge. One way to overcome this and to include all stakeholders, was through individual meetings the project officer held with the primary care team, clinical nurse managers, respiratory CNS and the respiratory team.

Figure 3. Tree representation of action cycles
• **Presentations:** details and progress of the project were presented to medical and nursing respiratory teams as well as the Community Specialist Palliative Care services in the hospice.

• **Education/training sessions:** two collaborative education/training sessions were held with the hospice and the Respiratory Assessment Unit. An evaluation of the training day showed a high level of satisfaction amongst participants and it is planned to repeat the session.

• **Dissemination:** considerable effort was made to disseminate details of the project through a total of 11 oral and 14 poster presentations at national and European respiratory and palliative care conferences. Publications about the project have been in nursing, general practice, health and palliative care newsletters, a chapter on the project is included in an academic book on action research and palliative care and there is a collaborative approach to the preparation of articles for peer-reviewed journals.

2. **Education Survey**

From the outset it was evident that education would play a key role in the project. To ascertain the need for palliative education the total population of staff (doctors, nurses, health care assistants and physiotherapists) working on the respiratory ward were invited to complete the Palliative Care Education Needs questionnaire and the willingness of the clinical nurse managers to take on the data collection ensured a response rate of 86%. Only 7% of the respondents reported any education in palliative care and 93% would like to have palliative care education (Figure 4).

![Figure 4. Percentage participants who currently have a qualification in palliative care and percentage interested in attending education](image-url)
Other findings included:

- **83.3%** reported that they discuss death and dying with patients
- **89.2%** reported that they discuss death and dying with relatives BUT 55% did not feel adequately educated to do so.
- **82.4%** identified a lack of support when a patient dies and reported that this needs further development.

There were two direct outcomes from the survey:

<table>
<thead>
<tr>
<th>1. Palliative Care Education for Respiratory Staff</th>
<th>2. Death Reviews</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Session</strong></td>
<td>Regular meetings (every 4-6 weeks) are conducted on the ward to discuss patients who have recently died. The meetings are opportunities to reflect on a patient’s end-of-life care in a supportive learning environment and they centre around four questions:</td>
</tr>
<tr>
<td>Final Journeys 1: Developing Awareness in End-of-Life Care. See page 20, no 1 for more details.</td>
<td>• What went well in the care of this patient and their family at the end-of-life?</td>
</tr>
<tr>
<td>Final Journeys 2: Developing Communication Skills in End-of-Life Care</td>
<td>• What didn’t go well?</td>
</tr>
<tr>
<td>Symptom Management in Advanced Respiratory Disease (planned)</td>
<td>• What would I do differently?</td>
</tr>
<tr>
<td>Final Journeys 3: Breaking Bad News (planned)</td>
<td>• Would the way this person died be acceptable to me?</td>
</tr>
</tbody>
</table>

From left: Final Journeys Facilitators Angela Edghill (Irish Hospice Foundation) & Elaine Clifford (St. James’s Hospital) at training in St. James’s Hospital, April 2011.
3. **Multidisciplinary Team Meetings**

As a way of reviewing respiratory patients with potential palliative care needs, monthly multidisciplinary team (MDT) meetings were established. A few days before each meeting all relevant staff were emailed and invited to briefly present any respiratory patients whom they felt had palliative care needs. Those invited were from:

1. **The Hospital Respiratory Team**  
   *Respiratory consultant, Registrar and SHO, Respiratory CNS’s and CNM’s from both the ward and the Respiratory Assessment Unit and physiotherapist*

2. **The Hospital Palliative Care Teams**  
   *Palliative Care Consultant and Palliative Care CNS*

3. **The Hospice**  
   *Palliative Care Advanced Nurse Practitioner*

4. **The Community**  
   *General Practitioner*

The meetings were brief (30 minutes) and allowed for all those involved with a patient to discuss his/her care so that informed and efficient decisions could be made. An attendance list and record of outcomes was kept (see Figure 5). In total, 10 MDT meetings were held with an average attendance of 9 people and on average 5 cases were discussed per meeting.

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**Figure 5. Frequency of outcomes from first eight multidisciplinary team meetings**

- Teams updated on patient status
- Respiratory Assessment Unit follow-up
- Formal referral to SPC
- Referral to hospice breathlessness clinic
- SPC team to review patient
- Commence palliative medication
- Referral to day hospice
- Referral to SPC outpatients
- Referral to hospice inpatient
- Referral to community SPC service
- Referral to regional SPC team
4. Interviews with Patients

The rationale for conducting interviews with patients and families came from a strong desire from the steering committee that the patient and family voice should be heard. The aim therefore was to capture the lived experience of patients with advanced respiratory disease and their attitude to palliative care. It was decided to conduct interviews with five patients in their own homes and to invite family members or carers to take part. These interviews took place one year into the project and again at the end of the project.

First set of interviews

Five patients agreed to take part in the interviews and three included a family member (husband, wife and son). All five participants had COPD as their primary diagnosis, were at stage three or four in their disease and all were on long-term oxygen therapy. None had been referred to any specialist palliative care service. All of the interviews were transcribed verbatim and NVivo 8 was used to facilitate the thematic analysis of the data. The results presented here will focus specifically on the themes in relation to specialist palliative care services.

<table>
<thead>
<tr>
<th>Conversations about Care in the Future</th>
<th>Knowledge of Palliative Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any questions in relation to future care or conversations in the future were either avoided or deflected. It seemed no one wanted to have conversations about the future.</td>
<td>All of the participants equated the term palliative care or the palliative care team with end of life and cancer. Yet when it was explained in terms of managing symptoms and improving quality of life there was an openness to seeing it in this way.</td>
</tr>
</tbody>
</table>

“I don’t even think about that now”. (Patient 5)  

“I always think of palliative care as just cancer.” (Patient 1)

“Well, I actually don’t know what kind of options there are. And I suppose I like to think that’s a way down the road.” (Patient 4)  

“I mean this palliative care – if that was a help, certainly if there was help there, it would be appreciated.” (Family Member 3)
Interviews at end of project

These interventions were conducted with five patients who had experience of at least one of the following palliative care services; day hospice, respite and breathlessness clinic.

First Conversations

Everyone remembered the first time that a specialist palliative care referral was mentioned. The association of the hospice with dying and cancer still pervades and this association also applies when morphine is first mentioned.

Palliative Care Services Utilised

All participants mentioned the physical elements of the day hospice; the transport provided, the tea and fresh scone on arrival, having massages, physiotherapy, aromatherapy, meetings with the doctors and nurses and the dinner and refreshments that were made available. Overall, it was the sense of being cared for and well looked after that came through all of the comments.

“Frightening when he said hospice and immediately he said Harold’s Cross I said that’s it, where is the cancer?” (Patient 5)

“They treated you as if you weren’t sick yet they knew you were sick. They aren’t making a fuss over you but they were making the fuss”. (Patient 2)

“I remember it frightened me, the mention of it, it also frightened me more when they said morphine, I think most people think morphine is for people on the way out” (Patient 4)

Making a Difference

There was an overwhelming high level of satisfaction with the palliative care services that people availed of in the hospice. The positive impact on the participant’s quality of life was evident. When asked what made it so good participants mentioned; the sense that there was holistic and continuous care provided, the social aspect of getting out for the day and being with other people and importantly, the staff in the hospice and the sense that they couldn't do enough for them.

There was a real sense that the referral to the palliative care services makes a difference to the life and health of the participants. It helped with breathlessness through exercises and medication. For some it took away some of the anxiety they were feeling and helped to restore their confidence in the management of their illness. Participants also felt that they understood more about their medication (e.g. inhalers and the use of morphine) which has reduced their anxiety levels about their use. For some it has given them a sense of comfort, that they are receiving excellent care and will continue to do so and several mentioned that it has taken away their fear of the future.

“I feel I’m better for it [oramorph] actually, before I wasn’t functioning hardly, now I’m able to get up and walk around, I find it a lot easier on myself.” (Patient 4)

“It gave you an idea what the future might hold and how you could deal with it and that was comforting in itself.” (Patient 3)
5. Respiratory Palliative Care Pathway for Patients

From the outset, developing a referral protocol and a care pathway was a high priority. It was only towards the end of the project that this became a reality - when palliative care had started to become embedded in respiratory care. The pathway was developed through several meetings of a multi-site, multidisciplinary team. After numerous revisions the final version (figure 6) is currently being piloted in St. James's Hospital.

Figure 6. Respiratory Palliative Care Pathway
Evaluation is an integral part of action research\textsuperscript{19}, so throughout each action cycle of this project, there was a process of reflection and evaluation on the part of the project officer and the steering committee. This lead to the development of some action cycles (e.g. education) or the suspension of others (e.g. information leaflet not developed as felt sufficient leaflets on specialist palliative care services already available). Several methods of evaluation were conducted using Øvretveit’s (2002)\textsuperscript{23} five features of evaluation; direct comparison of action cycles with original goals, and process evaluation. Table 2 examines previously identified barriers to specialist palliative care\textsuperscript{8} with actions arising from the project.

### Table 2. Identified barriers to the provision of SPC\textsuperscript{8} and relevant action cycles

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unpredictable disease trajectory</td>
<td>Although this will always remain the pattern in advanced respiratory disease, the introduction and development of the Respiratory Palliative Care Pathway will provide guidance and steps to take within the disease trajectory.</td>
</tr>
</tbody>
</table>
| Lack of a definition of referral criteria     | Literature review synthesised the evidence from 9 publications to identify referral criteria. Four main criteria are; FEV\textsubscript{1} <30% predicted, recurrent hospitalisations, poor functional status and increased symptom burden despite optimal management.  

The use of the surprise question has also been identified and is used by respiratory staff. |
| Lack of disease specific expertise            | Education sessions have been provided to respiratory staff through presentations about the project and Final Journeys training.  

Respiratory specific education has been delivered to palliative care staff.  
Multidisciplinary team meetings provided format for specialists to learn from each other. |
| Services being overwhelmed by large numbers of non-cancer patients | Although the audits have shown a steady increase in the number of referrals to SPC services, the actual number of patients remains small and to date SPC have reported that they have not been overwhelmed. |
A focus group conducted with the steering group and a survey with the Respiratory Assessment Unit at the end of the project identified that:

Building relationships and collaboration between sites and teams is at the cornerstone of this project and equally the areas that haven't brought about change are due to the lack of engagement by individuals and teams.

‘There are effects that we can’t measure... [for example with] the MDT meetings, there was so much learning that happened within the RAU and staff on the ward and that does filter through and the relationships that were built.’ (Respiratory CNS)

Using action research methodology was an important contributor to the outcomes of the project. Although it is difficult to measure outcomes, its value in terms of directly impacting on patient care was noted.

‘I do think that it would have been less effective if it had been a traditional research project ... If we did a straightforward research project with p values, you’d be able to stand up at the end of the day and present the data but that would have no impact on the patient.’ (Respiratory Consultant)

The main change in palliative care interventions have been with outpatients and this change is centred around developments in the RAU and their relationship with the hospice. There has been a marked lack of change in the referral pattern for inpatients. Possible reasons for this were identified as: the retirement of the SPC consultant during the project and the lack of a replacement; the lack of uptake from the medical teams on any of the educational initiatives; the timing of the care pathway towards the end of the project and simply the early location of project within an outpatient service.

Overall, there is a sense that the project has achieved many of its goals and that ‘the general ethos (in caring for patients with advanced respiratory disease) has changed’ (CNS).
CONCLUSIONS

1. Developing a palliative care approach to caring for respiratory patients is feasible.
2. This project has brought about changes in patient care and referrals. This is particularly true for outpatients with inpatients not benefiting to the same degree.
3. Successes have resulted from the relationships and collaboration between sites and teams. This collaborative approach has led to the development of new knowledge:
   ‘Respiratory and palliative care knowledge based values and world views have come together and we have generated a new practice based knowledge base’ (Respiratory CNS)
4. What was echoed from the evaluations was that the greatest achievement is the shared approach that now exists between the hospice and the RAU.
5. The use of action research enabled the inclusion of all relevant stakeholders to be part of the changing work practices and having a dedicated project officer facilitated the introduction and evaluation of these changes.
6. There were many other actions directly and indirectly related to this project:
   • Pulmonary rehabilitation session on ‘Living with a Chronic Illness’
   • RAU Supportive Care Package for patients
   • Priority review clinics held by consultant for patients with advanced respiratory disease
   • Hospice Friendly Hospital Programme developments throughout the hospital
7. Due to the time and resource limitations of this project it has not been possible to address all relevant issues e.g. changing the patient pathway through emergency department for each hospital admission and building closer links with primary care.
8. Further research is needed to evaluate the respiratory palliative care pathway and to analyse the changes in education and attitudes through follow up questionnaires.
9. A meta analysis of the organisational learning from all three action research projects is underway and chart audits examining changes in patient referrals, medication, quality of life and admission rates is planned for 2013.
10. Most importantly, patient interviews have shown that palliative care makes a difference to patient lives.
<table>
<thead>
<tr>
<th>WHAT WE KNOW</th>
<th>WHAT THIS ADDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients with COPD have a higher disease burden than those with lung cancer</td>
<td>Respiratory staff want education on palliative care</td>
</tr>
<tr>
<td>Main barrier to palliative care in advanced respiratory disease is the unpredictable disease trajectory</td>
<td>MDT meetings improve communication between teams and sites</td>
</tr>
<tr>
<td>Recognition in the literature that a new model/approach is needed in chronic disease management</td>
<td>Death reviews can be part of routine clinical practice</td>
</tr>
<tr>
<td>There are a lack of evidence and practice based models</td>
<td>The patient care pathway shows that generalist palliative care can be delivered by the respiratory team with referral to specialist palliative care when appropriate</td>
</tr>
</tbody>
</table>
FURTHER RESOURCES

1. Related to Project

- [www.hospicefoundation.ie/what-we-do/palliative-care-for-all/](http://www.hospicefoundation.ie/what-we-do/palliative-care-for-all/)
  This provides information on all three project areas; dementia, heart failure and advanced respiratory disease alongside education courses in Ireland and further resources.

- [www.hospicefriendlyhospitals.net](http://www.hospicefriendlyhospitals.net)
  Provides information on programme, provides details on resources such as end-of-life symbol and ‘Final Journeys’ programme which aims to enhance the quality of interactions between patients/residents at end-of-life, their families and staff. These courses are highly interactive and further information is available by emailing finaljourneys@hospicefoundation.ie / Tel 01 679 3188.

**Pulmonary Rehabilitation**

- [www.Livingwellwithcopd.com](http://www.Livingwellwithcopd.com) (password copd)
  Living Well with COPD™ is a self-management education program developed to help patients with Chronic Obstructive Pulmonary Disease (COPD) and their family in managing their disease.

  Australian Lung Foundation pulmonary rehabilitation toolkit

2. Advanced Respiratory Disease and Palliative Care

- [www.irishthoracicsociety.com](http://www.irishthoracicsociety.com)
- [www.ersnet.org](http://www.ersnet.org) (European Respiratory Society)
- [www.livingwithcopd.ie](http://www.livingwithcopd.ie)
  This website is designed for patients and their families who want to learn more about living with COPD – what it is, how it is diagnosed and treated, available supports and simple steps that will ease symptoms and improve quality of life.

- [www.impressresp.com](http://www.impressresp.com)
  Combined website of British Thoracic Society and Primary Care Respiratory Society

  Contains details of booklet ‘Difficult Conversations – Communicating with people with Chronic Obstructive Pulmonary Disorder about the End of Life’.
REFERENCES

1. HSE/IHF. (2008). Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks. Dublin: HSE/IHF.

2. GOLD Guidelines: Executive Summary: Global Strategy for the Diagnosis, Management and Prevention of COPD. GOLD.


