

Integrated Respiratory Project - Palliative report – July 2020

- Summary of input and outcomes
- Patients reviewed in palliative MDTs – City and North
- Patients receiving palliative support
- Patients added to palliative care register with advance care plans in place
- Patients achieving PPD

Introduction

Palliative care was provided as part of the Integrated Respiratory project through close collaboration between IRT physiotherapist, Occupational Therapist, GPs, community palliative care clinical nurse specialists, psychologist/CBT therapist and palliative medicine consultant from Sobell House and Katharine House Hospice. Respiratory nurses were involved as much as possible.

The Palliative multidisciplinary meeting took place weekly in the City area and bi-monthly in the North area and was attended by the above-mentioned professionals. All patients in the project were recorded on an excel spreadsheet and discussed regularly in the meeting, depending on their identified needs and how well symptoms were managed. Colour coding was used to identify patients with urgent needs and those who were stable. Patients remained on the list and were monitored throughout the project. This ensured early identification of patients with end stage respiratory disease and provided holistic/integrated end of life care. Patients received timely intervention from the most appropriate profession, including psychological support. Patients were encouraged to explore their wishes in relation to their illness and to complete an advance care plan, if they wished. Representation from primary, secondary and community care allowed an integrated approach and recording of the discussions including actions in the patient records across the different sectors.

Feedback from IRT North – Katharine House Hospice palliative care team

A total of 34 patients were regularly discussed at the bimonthly MDT in the North, from July 19-July 20. This report covers from July 19 to Feb 20, as requested.

25 patients received direct input from the palliative care community team service (CNS +/- medical review); 6 were referred since Feb 20 therefore not included & 2 pts were already known to KHH community service.

Of these 19, 10 of whom have died.

Palliative care team assessment included completion of a validated Outcome Tool, Integrated Palliative Outcome Scale ('IPOS'), part of the Outcome Assessment & Complexity Collaborative (OACC) suite of measures. This captures the issues raised by the patient as the highest priority to address and included:

- fatigue, weakness, poor mobility
- Shortness of breath
- Psychological issues, such as 'I have no fight left in me', anxiety around cancelling of a CT scan, 'Keeping away from crowds, not going out, risk of catching infection'
- Pain
- Poor appetite
- Most patients rated as 'high' that friends and family were anxious about their illness

Input included:

- evaluation of anxiety & low mood with HADS; titration of antidepressant medication as appropriate
- Opportunity to explore understanding of illness, discussion around end of life preferences & ACP, fears around the dying process
- Psychological support, including in one case particularly around adjustment to transplant no longer being a management option
- Decisions around CPR including DNACPR documentation in community if appropriate (CNSs have completed competency training to enable them to complete SCAS DNACPR documentation)
- Arrangement of 'just in case' subcutaneous medications for those wishing to be cared for at home
- Opioid titration for breathlessness +/- pain; use of benzodiazepines for breathlessness & anxiety, where appropriate
- Management of constipation
- Management of nausea
- Support by phone through COVID shielding period, including support through a new diagnosis of malignancy for one patient
- Referral to community support services, such as the Lawrence Home Nursing Team, to enable meeting PPD
- Carer support

Reflections on the IRT MDT

1 It has been extremely helpful having an OT as part of the team as this has enabled a practical response and proactive approach to addressing issues of concern for patients and families and not a service we readily have access to at the hospice.

2 In terms of ACP this has been offered to all pts but for some this has been difficult to explore and whilst this is desirable it also needs to be paced and done at a time that is right for the patient. If this is rushed or communicated poorly the risk is a poor outcome or it becomes an obstruction to achieving a constructive conversation at a later date, often due to fear. It is important for all staff who are caring for those with life-limiting illness to be skilled in having these conversations, so they can be addressed in a timely way and when this is right of the patient – often best done with a HCP whom they trust and have an established relationship with. ACP can be like planning the unplannable, particularly for a group of patients with recurrent infective episodes which may or may not have a reversible component. It is also imperative that ACPs are accessible at the time of need and that if changes are made these are updated to ensure accuracy – there is a risk that without joined up IT systems this may not be the case

3 The families of the group of patients who have died have benefitted from being offered bereavement support via the hospice.

4 Coordinating support is important so that HCPs do not all contact the patient at the same time as it may be preferable to stagger input rather than overwhelming the pt. Shared patient records / IT system would greatly improve this continuity.

5 Support was offered to patients during the COVID period, usually by telephone. Whilst this might not form part of evaluation this group would potentially be very isolated during this time; Also, ACP

specific to COVID was attempted with all pts with palliative team input & recorded on OUH EPR template as appropriate, to inform acute services if hospital admission occurred.

Feedback from IRT City

A total of 69 patients were regularly discussed at the weekly MDT in the City, from July 19-July 20.

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Analysis of deaths under IRT team March 2019 – April 2020

In total 49 deaths:

- 27 (55%) died in their usual place of residence i.e home, nursing home, care home
- 15 (31%) in hospital
- 7 (14%) in hospice

Review of place of death:

Deaths in usual place of residence 27 deaths in total:

- **At home: 20**
 - 16 had completed advance care plans (ACP) with preferred place of care/death (PPC/D) as home
 - 3 had started ACP discussions but were still in progress
 - 1 had declined to discuss ACP
- **Nursing Home/Care Home: 7**
 - 3 had completed ACP where PCC/D was a nursing home
 - 4 ACP discussions were in progress

Deaths in hospital: 15 deaths in total

- 4 patients had no ACP or ACP in progress (1 patient under oncology)
- 4 patients PPC/D: home/NH/hospice - *1 patient died whilst awaiting discharge from hospital for EOLC*
- 6 patients had an ACP where patients wanted full escalation/admission to hospital if became acutely unwell

Deaths in hospice: 7 deaths total

- 3 patients had no ACP/undecided - *2 of those patients were under oncology*
- 4 patients PPC/
○ D: home/hospice

Comparison of place of death

Place of death	IRT (2019)	England (2018)	Oxfordshire CCG (2018)
Home	41%	23.80%	23.3%
Care home	14%	22.50%	28.30%
Hospital	31%	45.4%	38.4%
Hospice	14%	5.90%	7.20%

(Public Health England end of life care statistics 2018)

Review of advance care plans and impact on place of death

Patients under the IRT team who had completed ACP – 31 (63%)

Patients with ACP in progress/declined/No ACP – 18 (37%)

- 9 were in progress
- 1 declined to discuss ACP
- 8 had no ACP recorded

Of these 4 died in hospital, 3 in hospice, 4 in nursing home, 3 at home, 4 unknown

Patients where place of death was known – 49 patients

29/49 (59%) of patients died in their PPC/D (including those who wanted hospital admission/full escalation)

- 16 died at home as per their PPC/D
- 6 died in hospital and wanted full escalation to hospital if became acutely unwell
- 4 died in hospice as per their PPC/D
- 3 died in NH as per their PPC/D

Patients with completed ACP – 35 patients

- 28 patients out of 35 (**80%**) died in their PPC/D
- 3 patients died in hospital where PPC/D was home
- 3 patients died in hospice where PPC/D was home
- 1 patient died in hospital where PPC/D was nursing home

Conclusion

More patients who were under the IRT palliative MDT died in home or hospice compared to the Oxfordshire CCG and country wide average. However, we should bear in mind that the Oxfordshire CCG and country wide statistics is of all deaths– expected and unexpected.

The majority of patients under the IRT palliative care MDT had a completed advance care plan and these patients were more likely to die in their preferred place of care/death with the majority of these deaths being their usual place of residence

Palliative Integrated Respiratory Team (IRT) Project - Advanced care plans (ACP) analysis

Data regarding advance care plans was taken from the IRT palliative Multi -Disciplinary Team (MDT) spreadsheet, which was updated at the MDT meetings, which occurred weekly in Oxford City and fortnightly in Oxford North. Patients included in this data are patients who were under the palliative IRT MDT from March 2019 to June 2020. Initially the data examines patients who were alive and still on the active caseload when the project finished in June 2020 then goes on to review ACPs in patients who died under the IRT palliative team.

Oxford City active caseload – total no of patients 37

Completed ACP: 24 (65%)

In progress: 8 (22%)

Not done: 5 (13%)

Reasons for ACP not being completed:

- 3 patients declined to have an advanced care plan conversation
- 2 had no reasons recorded

DNACPR decision recorded: 27 (73%)

No DNACPR decision recorded: 10 (27%)

- Several of these patients rescinded the DNACPR decision or wanted to be for resuscitation

Oxford North active caseload – total no of patients 18

Completed ACP: 14 (78%)

In progress: 0

Not done: 4 (22%)

Reasons for ACP not being completed:

- 3 patients declined to have an advance care plan conversation when offered

DNACPR decision recorded – 12 (67%)

No DNACPR decision recorded – 6 (33%)

- Several of these patients rescinded the DNACPR decision or wanted to be for resuscitation

Advance care plans for patients who died across Oxford City and Oxford North

Patients who had completed ACP – 35

Patients with ACP in progress – 9

Patients with no ACP - 9

- 1 declined to discuss ACP
- 8 had no ACP recorded

Total Advance care plans across Oxford City and Oxford North (for patients alive and those who have died)

Advance care plans for 104 patients in total were reviewed:

Patients who had completed ACP - 69 (66.3%)

Patients who had ACP in progress – 17 (16.3%)

Patients with no ACP – 18 (17.3%)

Impact of ACP on place of death for patients who died under the IRT (March 2019 – April 2020)

Patients who died under IRT with completed ACP – **35 patients**

Of these 28 out of 35 patients (80%) died in their PPC/D

Challenges & Conclusions

Severe chronic pulmonary diseases are progressive and debilitating illnesses characterised by loss of function, progressive dyspnoea and frequent exacerbations. Predicting individual prognosis and disease trajectory in this patient group is challenging, which can make advance care planning conversations difficult for healthcare professionals to initiate.(1).

Indeed one study interviewed 143 healthcare professionals (109 general practitioners, 25 nurses, 7 physiotherapists and 2 consultant physicians) where the majority cared for patients with COPD weekly, but only 23% had initiated ACP with a patient with COPD over the previous 6 months.(2). In comparison the Oxford City/Oxford North palliative IRT team had either completed or initiated ACP discussions in a total of 83% of their caseload (66% patients had completed advance care plans and 17% had advance care plans in progress). Furthermore, patients under the palliative IRT with a completed ACP were more likely to die in their preferred place of death, with 77% of patients with a completed ACP dying in their preferred place of death.

In conclusion the majority of patients under the palliative IRT MDT had formal and documented advance care plan. Furthermore, we have shown that having a documented advance care plan increased the likelihood of this complex patient group dying in their preferred place of death.

Future Proposal for the Palliative IRT MDT

This was a unique, forward thinking, patient centred MDT with diverse multi- professional representation including respiratory physiotherapist, respiratory consultant, occupational therapy, palliative care specialist nurse and consultant, psychotherapist and GP present. The meeting took a holistic approach regularly reviewing a patient's medical, psychological and social needs with an emphasis on providing support for ACP conversations, reducing hospital admissions and improving patient's quality of life. The meeting also provided a space for cross professional learning, teaching and development. Although we feel that more structured cross-discipline shared learning during the project would have been valuable.

Going forward we propose that the IRT palliative MDT meeting should continue in a formal, structured format but with a reduced frequency of a monthly meeting and a streamlined core MDT. The Core MDT team should comprise: respiratory physiotherapy, occupational therapy, respiratory nurse and palliative specialist nurse with support & input from medical and psychological specialists for complex patients from an appropriate healthcare professional i.e respiratory consultant, palliative medicine consultant, psychotherapist or GP (either the patient's own GP or previous IRT GP). We would recommend that the patients are presented by a healthcare professional to whom they are known, to optimise the depth of discussion. Continuing to run these meetings via Microsoft teams should allow for flexible & tailored representation as it would be easier for members to join the meeting to discuss specific patients as appropriate.

We would suggest ongoing evaluation of this MDT with meaningful outcome measures exploring the patient experience, cost and quality of care.

References

1. Stefan Andreas, Bernd Alt-Epping Advance care planning in severe COPD: it is time to engage with the future ERJ Open Research Jan 2018, 4 (1) 00009-2018; DOI: 10.1183/23120541.00009-2018
2. Meehan E, Sweeney C, Foley T, et al Advance care planning in COPD: guidance development for healthcare professionals BMJ Supportive & Palliative Care Published Online First: 04 November 2019. doi: 10.1136/bmjspcare-2019-002002