THE IMPACT OF AN INTEGRATED SUPPORTIVE CARE SERVICE FOR PATIENTS WITH INTERSTITIAL LUNG DISEASE

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BACKGROUND

Patients with progressive fibrotic ILD conditions such as idiopathic pulmonary fibrosis (IPF) have a poor prognosis (2-5 yrs) and a high symptom burden, comparable to advanced lung cancer (1).

Studies show that hospital interventions are common at the end of life - 1/3 of patients have end of life decisions made and for 74% this is in the last 3 days of life (2). Death is often 'unexpected' compared to patients with lung cancer (3).

DEVELOPMENT OF THE ILD SUPPORTIVE CARE SERVICE

Funding was secured for one year to develop an integrated service between Respiratory and Palliative Care.

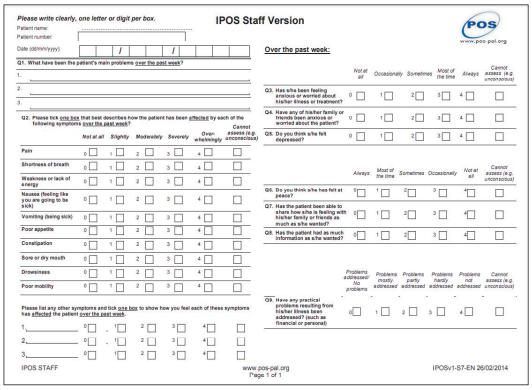
This allowed a specialist ILD nurse (WTE) and a consultant from Palliative Medicine (1 session) to provide a combined clinic with a respiratory consultant with a specialist interest in ILD.

AIMS:

- To improve symptoms by pharmacological and non-pharmacological methods
- To provide holistic care
- To improve ACP discussions and communication

METHODS:

- Fortnightly clinic / MDT with Respiratory & Palliative Care Consultant and Specialist nurse
- Telephone calls / video-consultations / home visits
- Symptom assessment using the palliative Care Outcome Scale (IPOS)
- Breathing – Thinking – Functioning model
- ACP discussions and request to GP to upload to Scottish National Key information Summary (KIS)
- Data collected on 50 patients within first 6 months of service



IPOS Staff Version

Please write clearly, one letter or digit per box.

Patient name:

Patient number:

Date (dd/mm/yyyy):

Q1. What have been the patient's main problems over the past week?

1.

2.

3.

Q2. Please tick one box that best describes how the patient has been affected by each of the following symptoms over the past week?

	Not at all	Slightly	Moderately	Severely	Over-whelmingly	Cannot assess (e.g. unconscious)
Pain	0	1	2	3	4	
Shortness of breath	0	1	2	3	4	
Weakness or lack of energy	0	1	2	3	4	
Nausea (feeling like you are going to be sick)	0	1	2	3	4	
Vomiting (being sick)	0	1	2	3	4	
Poor appetite	0	1	2	3	4	
Constipation	0	1	2	3	4	
Sore or dry mouth	0	1	2	3	4	
Drowsiness	0	1	2	3	4	
Poor mobility	0	1	2	3	4	

Please list any other symptoms and tick one box to show how you feel each of these symptoms has affected the patient over the past week.

1. 0 1 2 3 4
2. 0 1 2 3 4
3. 0 1 2 3 4

Over the past week:

	Not at all	Occasionally	Sometimes	Most of the time	Always	Cannot assess (e.g. unconscious)
Q3. Has s/he been feeling anxious or worried about his/her illness or treatment?	0	1	2	3	4	
Q4. Have any of his/her family or friends been anxious or worried about the patient?	0	1	2	3	4	
Q5. Do you think s/he felt depressed?	0	1	2	3	4	

	Always	Most of the time	Sometimes	Occasionally	Not at all	Cannot assess (e.g. unconscious)
Q6. Do you think s/he has felt at peace?	0	1	2	3	4	
Q7. Has the patient been able to share how s/he is feeling with his/her family or friends as much as s/he wanted?	0	1	2	3	4	
Q8. Has the patient had as much information as s/he wanted?	0	1	2	3	4	

	Problems addressed: No problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed	Cannot assess (e.g. unconscious)
Q9. Have any practical problems resulting from his/her illness been addressed? (such as financial or personal)	0	1	2	3	4	

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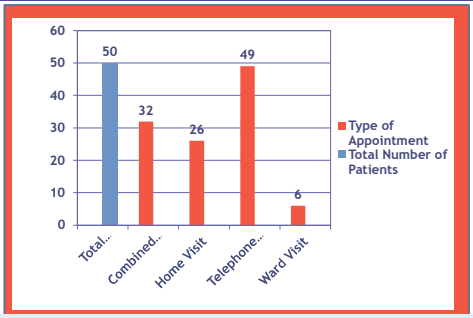
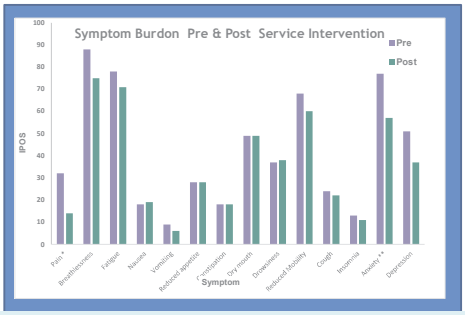
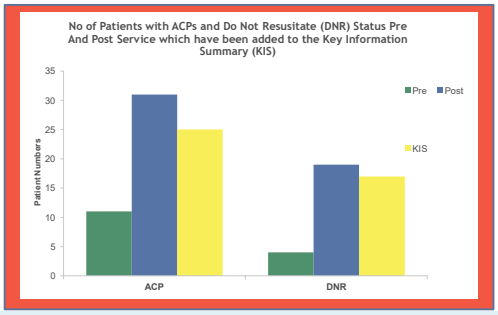
RESULTS AND CONCLUSIONS







Consultation Type: 32 /50 patients attended the combined clinic. Home visits, video and telephone consultations were also offered, with some patients receiving all types of consultation, dependent on need.

Symptom Assessment and Control: First and last IPOS scores were available for 33/50 (66%) patients. Symptom burden was high - most symptoms improved; pain (p=0.035) and anxiety (0.040) reduced significantly.

ACP: Pre-service 11/50 (22%) patients had ACP documented on KIS with DNA CPR documented in 4/50 (8%). Post-consultation, 31/50 (62%) had ACP documented (p=0.003). ACP was uploaded to the KIS in 25/31 (81%). DNACPR discussions were documented for 19/50 (38%) (p=0.008) with 17/19 (89%) of these uploaded to the KIS

Mortality: 11/50 (22%) patients died within the 6 months. Of these, 7/11 (64%) had documented PPD for home. This was achieved in 6/7 (86%).

PATIENT FEEDBACK: **"The ILD clinic and dedicated nurse is a first-class initiative. It is supportive, holistic, and proactive. Cannot fault or recommend enough".**

CONCLUSION -The integrated ILD Supportive Care service improves symptom burden for patients, supports patients and carers, improves ACP and may reduce unwanted hospital admissions at end of life

References:
1. Carvajalino et al, 2018
2. Rajala et al, 2016
3. Kim, Atkins et al 2019