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Judy Hawksworth
Administrator
Action for Pulmonary Fibrosis

13th October 2017

Dear Judy, Trustees and members

Re: Travel Scholarship for ERS 2017

I would like to express my sincere thanks to Action for Pulmonary Fibrosis for supporting my attendance at ERS Congress in Milan through the award of a travel scholarship. This is my ninth consecutive attendance at ERS and I have seen the nature and volume of research into IPF expand in depth and breadth over that period of time. Yet we still face challenges in optimising the quality of life for people afflicted with idiopathic interstitial pneumonia.

Learning from work conducted in COPD we undertook a series of exploratory workshops to find out if singing interventions should be modified for people living with fibrotic lung conditions. We also wanted to understand if singing combined with postural awareness, mindfulness techniques and relaxation could be beneficial for people living with fibrotic lung conditions. Working with Phoebe Cave, experienced music therapist, Adam Lewis post-doctoral research physiotherapist and Karen Taylor of Royal Brompton and Harefield Arts we delivered a 12 week iterative and bespoke programme. I was privileged to present our work on behalf of the team on Rhythm and Song: Breath management for participants with fibrotic lung conditions at a thematic poster session at ERS congress. The poster presented is appended below. The project was supported by a research grant from the BLF. Our poster was ranked in the top 3 posters by the chair Stephanie Mansell alongside Respiratory Physiotherapy Practice in Turkish ITU and Compensatory movement strategies during movements of the upper quadrant in patients with COPD in Portugal.

Our work generated a great deal of discussion – not only at ERS. I was invited to take part in a webinar with Elisabeth Estes of Three Lake Partners and Bill Vick from PF Warriors in the US to discuss the development of our programme. The webinar can be accessed at: <https://www.facebook.com/pfwarrior/>

As secretary to group 9.3 in Assembly 9 I had many responsibilities to attend to during congress in particular supporting the Nursing Group oral presentations and poster discussion sessions. There is a need to grow the nursing respiratory specialism pan Europe to ensure that the profession has a strong future and associated positive impact on clinical service delivery and clinical research.

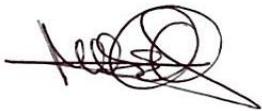
My chairing responsibilities were shared with Saskia Weldam post-doctoral researcher in Nursing Science at the University Medical Centre Utrecht and Katleen Leceuvre Specialised nurse in interstitial lung disease, University Hospital Leuven, Belgium. Subsequent to this Katleen was invited to write an article for ERJ Breathe on nursing perspectives. Both Saskia and Katleen are supporting the translation of the IPF Patient Reported Outcome measure.

Whilst the majority of discussions in the Delivering person-centred care across the spectrum of respiratory nursing session focused on COPD and Asthma, Geraldine Burge presented data from her unit on anti-fibrotic prescribing. Mrs Burge highlighted the important role ILD clinical nurse specialists play in supporting adherence to treatment in the early stages. We identified that shared pathways of care require further work.

Our poster discussion session: Nursing practice across respiratory care pathways gave rise to lively discussions. Bettina Korn, End of Life Care Coordinator at St. James's Hospital Dublin presented work on advanced life care planning using the Hospital One year Mortality Rating tool and identified learning needs for healthcare professionals to deliver information to patients in more effective and timely ways. As I write this report on the eve of Palliative Care world day I reflect on approaches that are needed to support clinical nurse specialists to support patients and families to live well with fibrotic lung conditions. If you are interested in this too do read our review published on line ahead of print on 13th October 2017 which offers an international perspective: [http://thelancet.com/journals/lanres/article/PIIS2213-2600\(17\)30383-1/fulltext](http://thelancet.com/journals/lanres/article/PIIS2213-2600(17)30383-1/fulltext) .

We also discussed the merits of telemedicine and tele-health in our poster session with the conclusion that mixed approaches are needed to respond to differing patient needs underpinned by investment in administrative support. The nursing group is the smallest group in Assembly 9 yet we have trebled the number of abstracts submitted in the last 2 years and more than doubled membership in the last 3 years. We are keen to continue this trend and value the support that Action for pulmonary Fibrosis offers, in particular, travel scholarships. Thank you.

Sincerely

A handwritten signature in black ink, appearing to read 'Anne-Marie Russell', with a stylized flourish extending to the right.

Anne-Marie Russell
Clinical Research Fellow



Rhythm and Song: Breath management for Patients with Idiopathic Interstitial Pneumonia (IIP): Pilot study

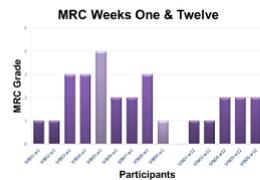
Phoene Cave¹, Karen Taylor¹, Adam Lewis², Nicholas S. Hopkinson², Athol U. Wells², Anne-Marie Russell¹

¹Royal Brompton and Harefield NHS Foundation Trust - London / UK ²National Heart and Lung Institute, Imperial College and Royal Brompton Hospital - London / UK

INTRODUCTION

- Breathlessness is a distressing symptom for which treatments are limited
- Benefits of singing for lung health in COPD have been demonstrated¹⁻³
- People diagnosed with IIPs often attend generic singing groups
- It is not known if a different approach is required for those with restrictive breathing patterns
- We set out to explore the usefulness of breathlessness management utilising singing techniques for breathing control, mindfulness and posture specifically in IIPs

RESULTS

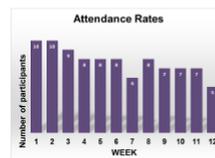
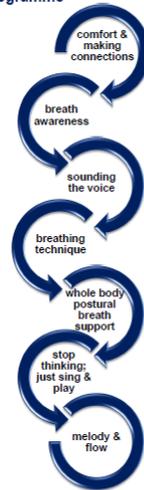


	Week 1 (n=10)	Week 12 (n=6)
• PHQ9	5.33 ±3.84	3.80 ±3.19
• GAD-7	2.11 ±2.42	1.60 ±1.67
• ETV Distress	1.50 ±2.82	2.40 ±3.31
• ETV Anxiety	2.17 ±3.24	2.70 ±3.51
• ETV Depression	2.22 ±3.44	2.20 ±3.62
• ETV Anger	1.50 ±2.14	2.20 ±3.21
• ETV Need for Help	1.56 ±2.04	1.20 ±2.41
• SGRQ Symptoms	54.15 ±23.23	48.60 ±26.83
• SGRQ Activities	58.38 ±30.49	51.23 ±41.06
• SGRQ Impacts	33.71 ±22.58	28.88 ±21.92
• SGRQ Total	43.97 ±28.00	30.18 ±20.64

Thematic analysis of Participant Diaries

Dimension	Quotation
Physical	My breathing has become regular and comfortable I realise how important posture is My own physical reactions to the exercises is improving Relaxation techniques help to improve my breathing
Psychological	The techniques I have learned helped carry me through a stressful week My attitude to how I breathe has changed Feeling fearful about the group coming to a close Emotional & mental stress gets put to one side - feeling refreshed & renewed again
Cognitive	I found the class this week more technical and very interesting We are so absorbed in doing what we are learning, the outside world and concerns disappear More progress with new songs that stretch technique and temp
Social functioning	I would not miss it - all my friends are there The camaraderie and friendship The best thing is doing the singing & getting to know other sufferers of this disease

Figure 1. Principles underpinning the Programme



This presentation is supported by an Action for Pulmonary Fibrosis Travel Award

METHODS

- The Rhythm & Song programme was written and delivered specifically for patients with IIP by an experienced Music Therapist
 - informed through prior knowledge & in discussion with UK based ILD specialists
- A clinical researcher with condition specific knowledge screened and recruited 10 patients (7:3 men:women) & participated in some sessions
- The programme was delivered in a tertiary centre. Patients were advised to defer any participation in Pulmonary Rehabilitation programmes
- Baseline spirometry was performed & repeated at week 12
- Participants completed the following questionnaires at baseline and week 12
 - SGRQ; PHQ-9; GAD-7; MRC Breathlessness scale; Emotional Thermometers Visual analogue Scale (ETV)
- An iterative** approach was taken to the 12 week programme of "Rhythm and Song" underpinned by core principles Fig 1. This approach combined appropriate musical, movement and mindfulness activity
- Participants consented to audio visual recordings of the later session
- At the outset participants were asked to set personal aims and objectives
- Weekly diaries recording reflections on each workshop were maintained by participants and music therapist & underwent thematic analysis

AGE	FVC	FVC%
72 ± 8	2.62 ± 0.68	78.14 ± 14.02
DLC _o	DLC _o %	CPI
3.61 ± 1.72	45.31 ± 20.61	48.71 ± 16.64

Week 1 - Week 12	Mean Change	Effect Size
• PHQ9	-0.6	-0.20
• GAD-7	-0.4	-0.16
• ETV Distress	-0.6	-0.21
• ETV Anxiety	-0.5	-0.15
• ETV Depression	-0.2	-0.21
• ETV Anger	-0.6	-0.28
• ETV Need for Help	0.30	0.14
• SGRQ Symptoms	-2.87	-0.12
• SGRQ Activities	-8.00	-0.02
• SGRQ Impacts	0.04	0.00

CONCLUSIONS

- Analysis of participant's diaries indicate that the 12 week Rhythm and song programme was enjoyable, educational and improved perceptions of breath management
- Social cohesion and shared experience were of particular importance
- Participants recorded lower scores for depression, and the need for help at the end of the programme and an improvement in their overall quality of life.
- Anxiety scores were conflicted according to GAD-7 and the ET-VAS
- MRC grade remained the same for the majority
- Questionnaire data should be interpreted with caution given the sample size.
- There was no meaningful change in FVC as measured by spirometry from week 1 - 12
- The study provides a positive baseline for which to plan & continue future work but further discussion is needed to optimise a robust end point model.
- This group ran through the autumn months which in retrospect was not the optimal time
- Future groups should over recruit to allow absences due to holidays and exacerbation
- ** Our work demonstrated that people with restrictive lung conditions require different breathing training than those with obstructive lung conditions. These differences must be fully accounted for when providing singing interventions.

References:

- Lewis A, et al Singing for Lung Health—a systematic review of the literature and consensus statement npj Primary Care Respir Med 26: 16080 (2016) doi:10.1038/npcrm.2016.80
- Lord V.M et al. Singing teaching as a therapy for chronic respiratory disease- A randomised controlled trial & qualitative evaluation. BMC Pulm. Med. 10, 41 (2010)
- Clift S et al Singing for Better Breathing Findings from the Lambeth and Southwark Singing and COPD Project Technical Report Sidney De Haan Research Centre for Arts and Health



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