FEASIBILITY-TESTING A CO-DESIGNED BREATHLESSNESS EPISODE RECOVERY PLAN FOR PEOPLE WITH COPD AND THEIR SUPPORT PERSONS

Muneeba T Chaudhry[1], Mary Roberts[2], John Hancock[3], Maureen Parkin[3], Lennette Ruttle[4], Marina Siemionow[4], Kate Smith[5], Jo River[1], Tracy Smith[2], Marie Williams[6], Kylie Johnston[6], Gerben Keijzers[7], Hancy Issac[7], Miriam J Johnson[8], Ann Hutchinson[8], Flavia Swan[8], Mark Pearson[8], Michael Crooks[8], Anna Keedwell[9], Slavica Kochovska[10], Joel Rhee[11], Eila Erfani, Ester Klimkeit[2], David Currow[10] Meera Agar[1], Tim Luckett[1]

1. Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT), Faculty of Health, University of Technology Sydney (UTS), New South Wales (NSW), Australia
2. Department of Respiratory and Sleep Medicine, Westmead Hospital, Sydney, NSW, Australia
3. Person living with COPD and breathlessness, Australia
4. Support person for someone living with COPD and breathlessness, Australia
5. Lung Foundation Australia, Australia
6. Adelaide University, Adelaide, South Australia, Australia
7. Gold Coast University Hospital Emergency Department, Gold Coast, Queensland, Australia
8. Wolfson Palliative Care Research Centre, University of Hull, Hull, East Yorkshire, UK
9. Palliative Care, Cabrini Health, Carlton, Victoria, Australia
10. Flinders University, Adelaide, South Australia, Australia
11. School of Population Health, Medicine & Health, University of New South Wales (UNSW), Sydney, NSW, Australia

KEYWORDS

COPD, dyspnoea, breathlessness, self-management, patient education, qualitative

EXECUTIVE SUMMARY (100 words maximum)

Episodes of worsening breathlessness are common and distressing for many people with COPD. This study tested and refined the acceptability and feasibility of a co-designed, non-pharmacological breathlessness episode recovery plan and supporting resources across Respiratory, Palliative Care, and Emergency settings. Thirty patients and 12 clinicians participated. Patients and clinicians valued the structure provided by the plan, but some patients struggled to retain key information, and clinicians identified workflow challenges. Iterative refinements improved usability. Findings support acceptability and inform ongoing efforts to improve feasibility, including an 'app' version. Final resources will be available from the Lung Foundation Australia by year-end.

INTRODUCTION

Episodes of worsening breathlessness are common and distressing for many people with chronic obstructive pulmonary disease (COPD) and their families. Non-pharmacological strategies that address both breathing and thinking can be used to self-manage these episodes.

This study aimed to test and refine the acceptability and feasibility of a non-pharmacological breathlessness episode recovery plan and supporting resources co-designed with people with COPD and support persons in partnership with Lung Foundation Australia (LFA). The plan is based on the mnemonic 'Do Your 5': *stop, think, position, breathe out slowly, and airflow/cool*.

HIGHLIGHTS

- Patients and clinicians alike valued the plan's structure.
- Patients most welcomed learning that breathlessness is not inherently harmful.
- Some patients struggled to retain information when presented with a longer plan.
- Iterative refinements, including a short-form of the plan, improved usability.
- Workflow constraints, especially in ED, were the main implementation barrier.

METHODOLOGY/ PROCESS

Feasibility testing and refinement of the intervention were conducted across two cycles within respiratory (primary), and palliative care and emergency department (secondary) settings. In cycle 1, the intervention comprised of a co-designed paper-based breathlessness plan and supporting resources including a user guide, and two clincian education videos to facilitate delivery in clinical settings.

Clinicians delivered the intervention as part of routine care and audio-recordings where taken where possible of the clinician-led plan-related education. Telephone interviews with patients were completed 1- and 4- weeks post-education. Focus groups canvassed clinician perspectives. Transcripts were analysed qualitatively, using Sekhon et al's (2017) framework for acceptability.

RESULTS/ OUTCOMES

29 patients and 12 clinicians participated. Most patients had previously used at least one strategy but valued confirmation and structure. Key learnings included that breathlessness is not inherently harmful. Challenges included variable patient recall and engagement. Clinicians found the intervention acceptable but recommended refinements. Competing priorities and workflow constraints were identified as barriers, particularly in the emergency department. Across cycles, the plan was simplified, new clinician and patient training videos were added, and hand-held fans with a QR-link to the plan/resources were introduced.

CONCLUSION

This study demonstrates the acceptability of a co-designed breathlessness episode recovery plan. Findings inform ongoing efforts to improve feasibility of implementation. Once implemented, the plan has the potential to improve experiences of worsening breathlessness in COPD by better supporting self-management and enhancing clinical care.

The team is currently undertaking a final cycle of testing, to include a co-designed 'app' version of the plan. All versions of the plan and implementation resources will be available from the Lung Foundation Australia (LFA) by the end of 2026.