CareSearch Project Research Studies Register: Registration Proforma	0196

Study Title: The Experience of Refractory Breathlessness

Brief description of the study: Introduction: Refractory breathlessness occurs at rest or on minimal exertion, and persists chronically despite optimal treatment of the underlying cause. Affected individuals struggle with the most basic activities of daily living. This condition remains under-treated and under-researched, despite its high functional burden and global prevalence. Objective: The aim of the study was to gain a greater understanding of the daily lived experience of refractory breathlessness. It was anticipated that a deeper insight into the impacts on daily activities would allow more effective occupational therapy interventions to be developed. Method: Participants were recruited from a Sydney-based outpatient Breathlessness Clinic between July and September 2017. All were over 18 years and been diagnosed with refractory breathlessness resulting from lung cancer or chronic cardiac and respiratory disorders. An exploratory qualitative approach was undertaken with individual, semi-structured face-to-face interviews covering areas such as disease progression, management strategies, and social implications. NVivo software was used to conduct thematic analysis. Recruitment continued until thematic saturation was reached. Results: Six participants were interviewed and four main themes identified. 1) Living on the Edge, referring to the extreme feeling of breathlessness experienced by patients; 2) Social Needs, describing the significance of social support; 3) Reduced to the Basics, referring to the effect breathlessness has on basic daily tasks, and 4) Sources of Security, describing the measures participants take to protect themselves from their own breathlessness. The importance of functional participation for improved engagement and quality of life was common across all themes. One significant intervention recognised was the use of a hand-held fan. Patients found the fan empowering and gave them a sense of self control to help manage their feelings of dyspnoea. Conclusion: These themes and insights provide scope to develop specific interventions and occupational therapy services incorporating self-management and equipment prescription for this group of people.

Study Methodology: (Please mark with an x which type of study methodology)

	Epidemiology
	Health Services / Health Economics / Quality Improvement
X	Qualitative, Observational or Descriptive
	Mixed Method
	Systematic Review
	Intervention: RCT
	Intervention: Comparative or cohort study
	Intervention: Case series

CareSearch is funded by the Australian Government Department of Health.

Project details:						
Funding source (Optional):						
Has the study received ethics approval?	**X**	Yes		No		Not applicable
Project starting date: March 2017						
Project completion date: October 2017						
Multi site:		Yes	**X**	No		Not applicable
Researchers						
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Associated publications / reports: Tieck K, Mackenzie L, Lovell M. The lived experience of refractory breathlessness for people living in the community. Br J Occup Ther. 2019 Feb;82(2):127-135. doi: 10.1177/0308022618804754. Epub 2018 Nov 6.						
Topics (Admin only): Allied Health, Dyspnoea, Cancer, Chronic conditions						