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## **The Lived Experience of Refractory Breathlessness**

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The University of Sydney in partnership with HammondCare Greenwich Hospital  
Outpatients Breathlessness Clinic

Discipline of Occupational Therapy  
Faculty of Health Sciences

Master of Occupational Therapy Research Proposal and Literary Review for  
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## **The Lived Experience of Refractory Breathlessness**

### **Abstract**

**Introduction:** Refractory breathlessness is breathlessness at rest or on minimal exertion that persists chronically even with optimal treatment of the underlying cause. Despite its burden and prevalence globally, symptoms remain under-treated and under-researched and those affected struggle daily with the condition.

**Aim:** The aim of the study was to gain a greater understanding of the lived experience of refractory breathlessness. Also, it was anticipated that a deeper insight into its impacts on daily activities would allow more effective occupational therapy interventions to be developed.

**Method:** A qualitative phenomenological approach using NVivo software, with one-on-one, semi-structured interviews and themes established through thematic analysis. The study recruited consecutive patients until thematic saturation was reached. Participants were recruited from a Sydney-based outpatient Breathlessness Clinic at a palliative care hospital.

**Results:** 6 participants were interviewed and 4 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, which describes the measures participants take to protect themselves from their own breathlessness. For each of the four themes, three to five subthemes were also identified through the analysis.

**Conclusion:** Of the 4 themes identified in this study, number 3 and 4 may represent the best targets for occupational therapy interventions. Patients noted the importance of functional participation for improved engagement and quality of life. There is scope to develop specific interventions for self management and equipment prescription given lack of published literature in this area.

**MeSH terms:** dyspnea, occupational therapy, chronic obstructive pulmonary disease, activities of daily living, palliative care.

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## **Section one: Literature Review**

## **Introduction**

Breathlessness is a commonly experienced symptom for people with a variety of malignant and non-malignant diseases (Chin & Booth, 2016). It is defined as: “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity. The experience derives from multiple physiological, psychological, social, and environmental factors, and may induce secondary physiological and behavioural responses” (American Thoracic Society, 1999, p. 322). This description captures the complex nature of breathlessness. It has also been described as the uncomfortable awareness of the need to breathe but the loss of the ability to breathe with ease or confidence (Booth, Burkin, Moffat, & Spathis, 2014).

Breathlessness is a common symptom for individuals living with advanced disease. However, the disease trajectory can vary greatly according to the underlying condition (Booth, Moosavi, & Higginson, 2008). While breathlessness is most obviously associated with exertion, in its severe forms and at the end of life it may continue even when the individual is at rest (Booth et al., 2008).

Dyspnoea is associated with cardio-respiratory, malignant and non-malignant disease as well as some conditions such as renal and neurological illnesses (Booth et al., 2014). The most debilitating form of breathlessness is refractory breathlessness (refractory dyspnoea), defined as “breathlessness at rest or on minimal exertion that will persist chronically despite optimal treatment of the underlying cause(s)” (Currow, Abernethy, & Ko, 2014, p. 393).

Conditions commonly associated with refractory breathlessness include chronic obstructive pulmonary disease (COPD), cancer, bronchiectasis and heart failure. Patients experiencing refractory breathlessness are often markedly debilitated by their medical condition. Some are in a stage of palliative care. It is important to note that a number of studies analysed in this literature review focus on one single condition such as COPD, heart failure or cancer (Booth et al., 2014).

Despite the severity and chronic nature of refractory breathlessness, as well as the number of people affected, it remains under-researched (Currow et al., 2016; Currow et al., 2010; Dorman et al., 2009; Maddocks, Reilly, Jolley, & Higginson, 2014).



## Search strategy

A comprehensive search strategy was conducted in order to identify the literature most relevant to this study (see Appendix). The electronic databases *CINAHL*, *Medline*, *OT Seeker*, and *Web of Science* were searched for this review using the following key search terms:

Dyspnoea, (short\* adj3 breath), breathless\*, (difficult\* adj2 breath\*), chronic disease, (chronic\* or refractor\* or persistent\*), severe, ((end or late) adj2 stage\*), self report, patient\* adj2 experience\*), exp “activity of daily living”.

English language was selected but publication dates remained undefined to include all potentially relevant literature. Over 750 articles were found. These articles were then title and abstract screened. The 70 remaining after abstract screening were reviewed in full and sorted relevant to this study. In addition, an extensive handpicking of articles and text books was conducted.

## Theoretical framework - The International Classification of Functioning, Disability and Health (ICF)

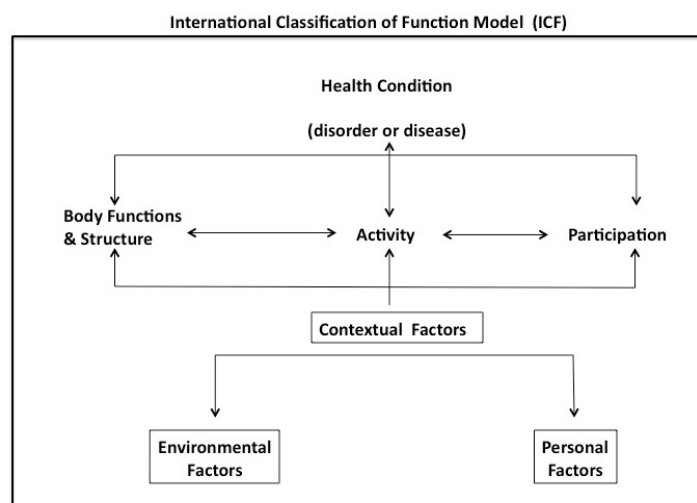


Image: (World Health Organisation, 2002).

The ICF is the World Health Organisation’s framework for health and disability (World Health Organisation, 2002). It is a bio-psychosocial model of human functioning and

disability that focuses on the functional and disability level of an individual. *Functional* meaning all body functions, activities and participation, and *disability* indicating impairment, activity limitations and restrictions in participation (World Health Organisation, 2002).

This model has a medical frame focusing on the health condition of the patient, but considers that condition in all dimensions such as impairment at the body and body part level, activity limitations, and societal level of restrictions in participation, as well as environmental and personal factors (World Health Organisation, 2002).

The framework is used alongside a medical diagnosis, meeting the reality of the varied needs of individuals with refractory breathlessness while also considering their personal experiences. A diagnosis alone cannot predict the level of care the patient will need (World Health Organisation, 2002). This model can help to recognise barriers and influences in the medical picture. An effective treatment plan can highlight functional capacities and intervention possibilities. This is particularly relevant from an occupational therapy perspective where the potential for meaningful intervention is great (Morgan & White, 2012).

The ICF is structured around the following broad components.

Three levels of human functioning:

- Body functions and structure (*Impairments* – for example, physiological functions of the body systems and anatomical parts of the body, such as lungs);
- Activities (*Limitations*, including difficulties an individual may have in carrying out their meaningful activities);
- Participation (*Restrictions* – problems an individual may experience involving life situations ranging from daily self-care to work, community activities, family or social responsibilities, access to medical support).

Contextual factors:

- Environmental factors (living conditions, social, physical, climate, occupational situation)
- Personal factors (age, co-morbidities, personality, levels of care and support, home safety, financial means).

The general principles that underpin the ICF as a health classification model include:

- Universality – this model can be used for all people regardless of health condition. Not labelling someone with a disability separately.
- Parity – Health conditions should not be separated by mental or physical classifications of function and disability.
- Neutrality – neutral stance when expressing positive and negative aspects of functioning and disability.
- Environmental factors – influencing at least somewhat both outcome and potential.

Individuals suffering with refractory breathlessness share an exceptionally severe symptom that limits their participation in activities and daily life, though perhaps to varying degrees due to their disease aetiology and their stage of illness (Booth et al., 2014). This model therefore creates an excellent framework to compare and analyse results of studies undertaken in this area. An example of the ICF applied to individuals with refractory breathlessness is located in the appendix.

### **Common underlying conditions associated with refractory breathlessness**

Breathlessness can have a significant impact on patients and carers, but hold different meanings based on diagnosis and progression of disease (M. Gysels & Higginson, 2011). Specific considerations based on those factors and also co-morbidities should be considered on an individual basis (Booth et al., 2014). However, research into the management of the effects of severe breathlessness, whatever the underlying condition, remains complex because of the limited number of studies and their power (Dorman et al., 2009). This is despite refractory breathlessness being recognised as the second most common symptom in patients with advanced chronic disease (Higginson et al., 2014).

#### Chronic Obstructive Pulmonary Disease (COPD)

The prevalence of COPD is increasing worldwide, accounting for more than three million deaths globally in 2015 (World Health Organization, 2016). COPD is a leading cause of death and disease burden (after heart disease, stroke and cancer) in Australia (Lung Foundation Australia, 2012), as well as being the second leading cause of avoidable hospital admissions (Glover, Page, Ambrose, & Hetzel, 2007).

Statistically in Australia, 7.5% of Australians aged 40 years or over have COPD with symptom progression that affects their daily lives. This increases to 29.2% of Australians over the age of 75 (Toelle et al., 2013).

COPD is a disease characterised by recurring periods of acute pulmonary exacerbations, with a slow and gradual deterioration in health and a reduction in pulmonary function that gradually leads to death (Murray et al. 2005). The primary cause of COPD is tobacco smoking, either active smoking or the inhalation of second-hand smoke (World Health Organization, 2016).

In a study of the frequency of general breathlessness in patients with COPD, 82% of the 49,438 patients in a 2014 study reported dyspnoea using the Medical Research Council Dyspnoea Scale, indicating the high prevalence of breathlessness associated with COPD. Of this >40% of the patients reported moderate-to-severe dyspnoea (Müllerová, Lu, Li, & Tabberer, 2014), indicating refractory breathlessness.

Some COPD patients require long-term oxygen therapy (Rabe et al.2007) to help manage the progression of the dyspnoea, but COPD affects more than just breathing. As the disease progresses it brings a myriad of other symptoms and issues associated with shortness of breath, such as anxiety due to the inability to comfortably breath (Booth, Silvester, & Todd, 2003; M. H. Gysels & Higginson, 2009), social isolation and loneliness due to difficulty mobilising (Ek & Ternstedt, 2008), as well as issues around dependency (Ek & Ternstedt, 2008) and the potential lack of meaningful activities in daily life (Williams, 1993).

## Cancer

Breathlessness may worsen more rapidly in patients with cancer than COPD (Booth et al., 2003) due to the nature of the underlying condition. Dyspnoea can occur with primary malignancy such as lung cancer or with a secondary cancer (Booth et al., 2014). Dyspnoea occurs in 90% of lung cancer patients (Booth et al., 2003) but is seen in 50-70% of other cancer patients with a marked increase in prevalence towards the end of life (Mercadante, Casuccio, & Fulfaro, 2000).

Intractable breathlessness can often develop rapidly in cancer patients who may have felt relatively well. This can be very hard for patients and their carers as the decline can be seen as very quick, especially when comparing an activity that the individual may have previously

been able to easily complete, but is now unable to do so due to the acceleration of their breathlessness symptoms (Booth et al., 2008).

As with COPD, management is complex and other factors including the individual's cancer treatment more generally would need to be considered (Cachia & Ahmedzai, 2008). When cancer is advanced, the severity and complexity of an individual's experience of dyspnoea should be considered alongside their disease status (Booth et al., 2008) and treated with a combination of drugs, oxygen and non-pharmacological interventions (Cachia & Ahmedzai, 2008).

### Heart failure

Heart failure is a chronic progressive cardiovascular disease with poor prognosis outcomes (Ryan & Farrelly, 2009). Breathlessness is the most prevalent symptom experienced by individuals with heart failure and often results in decompensation of the heart and recurring hospital admissions (Rich, 1999; Walthall, Jenkinson, & Boulton, 2017).

Unfortunately even with optimal pharmacological management, those with advanced heart failure have a mean life expectancy of only 3.1 years (Levy et al., 2006). The degree of breathlessness experienced in this patient group can be linked to mortality and undiagnosed heart failure (van Riet et al., 2014) as well as acute decompensation (Mentz et al., 2015). Therefore the importance of understanding the dyspnoea and recognising its symptoms and multi-effects is vital for all health professionals in order to more effectively treat and support this patient group.

### **Refractory breathlessness management**

Given its burden and prevalence globally, the symptoms of chronic refractory breathlessness remain under-treated. Individuals may feel they have to accept it as part of their disease, despite an evidence base for management (Currow et al., 2014). Symptoms of breathlessness are more than just a physical feeling of being unable to get enough breath or being unable to breathe easily and confidently. Other factors such as patient support, anxiety and psychosocial issues and the individual perception of breathlessness are part of the individual make up and discussed below. A better understanding of severe or refractory breathlessness is needed in order to understand the depth of individual's complex experiences (Booth et al., 2014).

### Support network for chronically ill

The role of a partner, carer, or family member assisting on a regular basis can make a profound difference to a person's life when living with such a debilitating condition. Research shows family and carers play a vital role in patient care during palliation (Addington-Hall, 2002).

The cost on the carer, however, can have a significant impact on their life (Seamark, Blake, Seamark, & Halpin, 2004). In the case of refractory breathlessness, watching a loved one with severe breathlessness can be frightening. It is difficult to witness a loved one struggle to breathe (Booth et al., 2003).

In one study by Booth et al. the role reversal for some patients and carers is discussed, as are the struggles for couples when the typical carer of the pair is now the individual being cared for (Booth et al., 2003). The significance of this study highlights the psychosocial complexity as well as the severity of the difficulties and struggles of the partner or carer as well as the patient. Carers are described as invisible victims as they helplessly watch, wait and feel anxiety while their partner struggles with his or her life and breath (Booth et al., 2003).

Caregiver burden has been reported to be high, particularly among patients with cancer, heart failure and COPD (Garlo, O'Leary, Van Ness, & Fried, 2010). This study examined the caregiver burden over time caring for someone with advanced chronic disease. Correlations showed when caregivers reported they needed more help with daily tasks and emotional support, they also reported higher carer burden than those who didn't feel they needed help in these areas (Garlo et al., 2010). Interestingly, carer burden has been found not to be disease specific but is a universal phenomenon across all three diseases where dyspnoea is a prominent symptom (Garlo et al., 2010). Interestingly, a carer support service is offered through an outpatient breathlessness clinic in London with promising results (Bausewein, Jolley, Reilly, Lobo, Kelly, Bellas, Madan, Panell, Brink, De Biase, Gao, Murphy, McCrone, & Higginson, 2012)

### Anxiety and breathlessness

It is unclear if anxiety triggers breathlessness (Dudgeon & Lertzman, 1998) or breathlessness triggers anxiety (M. O'Driscoll, J. Corner, & C. Bailey, 1999), or if both could be true. But certainly anxiety can be linked to dyspnoea (Dudgeon & Lertzman, 1998; O'Driscoll, J. corner, & C. Bailey, 1999). One study refers to the 'dyspnoea-anxiety-dyspnoea cycle': a

feeling patients identify when they experience the anxiety not as a cause of breathlessness but rather as a sign of breathlessness or as a trigger to manage the breathlessness (Meek, 2005). The emotional vulnerability expressed as anxiety by some individuals in this study was a precursor of an episode of increased breathlessness approaching that they could not avoid (Meek, 2005).

While interventions to enhance patients' self-management of their breathlessness may not improve the intensity of immediate symptoms, they are likely to offer a greater sense of self-mastery, reducing the fear, distress, anxiety and panic associated with refractory breathlessness, thus decreasing the often overwhelming symptom burden (Bausewein, Jolley, Reilly, Lobo, Kelly, Bellas, Madan, Panell, Brink, De Biase, Gao, Murphy, McCrone, & Higginson, 2012; Booth et al., 2008; Sherwood et al., 2005).

People suffering refractory breathlessness often find they have hospital related admissions (Glover et al., 2007), yet many emergency admissions to hospital are initiated due to the anxiety associated with their dyspnoea (Glover et al., 2007). What's more, end-of life refractory breathlessness may not be most effectively treated in hospital (Booth et al., 2008). Instead non-pharmacological interventions such as the use of a fan, anxiety reducing training, physical rehab (such as a breathlessness clinic can offer) and non-invasive ventilation can support better self-management (Booth et al., 2008; Davidson & Currow, 2010).

In a study specifically looking at the COPD patient group, it was found that anxiety and depression were associated with higher levels of fatigue, shortness of breath, and frequency of COPD symptoms (Doyle et al., 2013). This study reported a correlation with breathlessness symptoms and reduced functional capacity that seemed to increase the frequency of anxiety and depression among this patient group. Those with refractory breathlessness could be at a risk of anxiety and depression due to their reduced capacity and functional activity. Further study is recommended to confirm these findings (Doyle et al., 2013).

### Individual descriptors of breathlessness

Breathlessness is variously described by individuals. It possesses a number of different sensations and meanings to each individual describing their feeling of dyspnoea (P. Simon et al., 1990). Simon et al. developed a list of 15 descriptors of breathlessness that has been used in a number of studies exploring descriptors of breathlessness (Mahler et al., 1996; Wilcock et al., 2002), without a clear, distinctive or convincing pattern of description based on aetiology.

Within a group in Mahler et al's study, 51% of COPD patients (n=85) described their breathlessness as, "my breathing requires effort". This can be compared with Wilcocks's study where 44% of COPD patients (n=34) described their breathlessness as, "I cannot get enough air". Both studies used the same list of 15 descriptors. Of all the descriptors in the latter study, the most commonly used descriptor, irrespective of underlying condition, was, "I feel out of breath" (Lung cancer – pleural effusion and cardiac failure). The findings of these studies affirm the very subjective nature of breathlessness and how it is perceived by the individual experiencing it.

### **Treatment methods for refractory breathlessness**

As management of refractory breathlessness is best done with a combined non-pharmacological and pharmacological interventions approach (S. Simon & Bausewein, 2009), the need is evident for further exploration for allied health professionals engaged in treatment and research, particularly in relation to function and quality of life (Maddocks et al., 2014). The examples of studies linking refractory breathlessness with activities of daily living, including patients' perspectives of daily activities and participation (Morgan & White, 2012), are limited.

A systematic, evidence-based approach, combining the skills of a committed multidisciplinary team, would appear to improve the lives of these patients significantly (Booth et al., 2008). Booth et al. call for more research investigating the effectiveness of new interventions for more favourable management of this group, particularly non-pharmacological interventions.

### **Non-pharmacological treatment**

A number of non-pharmacological interventions exist in the current published literature, with varied levels of research quality. The Royal Australian College of General Practitioners (RACGP) list a number of interventions that could be considered for individuals suffering from severe dyspnoea. This does not consider the underlying aetiology, but only the symptomatic management of dyspnoea. Interventions mentioned include chest wall vibration, transcutaneous electrical nerve stimulation (TENS), walking aids, breathing techniques,



pacing and anxiety management (Wiseman, Rowett, Allcroft, Abernethy, & Currow, 2013). Pulmonary rehabilitation and the use of a handheld fan are discussed below.

### Pulmonary rehabilitation

Pulmonary rehabilitation has proved to be highly beneficial for patients suffering from chronic breathlessness (Nici et al., 2006; Ries et al., 2007). A variety of benefits have been reported to improve functional abilities such as a reduction in shortness of breath during exercise as well as improving exercise tolerance (Bianchi et al., 2011; Nici et al., 2006; Ries et al., 2007; Stulbarg et al., 2002; Troosters, Casaburi, Gosselink, & Decramer, 2005). Participants also report they struggle with their dyspnoea less when engaging in a pulmonary rehabilitation program (Parshall et al., 2012).

The primary purpose and benefit of pulmonary rehabilitation are the improvements participants can achieve in their exercise abilities (Bianchi et al., 2011; Gigliotti et al., 2003; O'Donnell, McGuire, Samis, & Webb, 1998; Stulbarg et al., 2002). It is still unclear, however, if the improvements in dyspnoea are due to improvements in conditioning, learning and applying pacing of activities, or whether participants become more desensitised to the varied respiratory sensations experienced on exertion during the program, or a combination of a number of the listed factors (Parshall et al., 2012).

Generally patients have other influencing aspects of their care when enrolled in a pulmonary rehabilitation program. These may include education from health professionals - including allied health - medication management, pacing of activities and breathing techniques that all contribute to the improvements alongside the exercise program (Parshall et al., 2012).

One study that did examine the role of occupational therapy (OT) in pulmonary rehabilitation (PR) for COPD patients showed promising results, identifying the value OT plays to improve patient outcomes (Lorenzi et al., 2004). This was done by measuring the number of functions lost using the Basic Activity of Daily Living (BADL) categories before and after rehabilitation. Aiming to establish whether PR plus OT - as opposed to just OT - has the potential for improvement for patients' daily activities, results showed patients in the PR+OT group had a significant improvement in BADL after the programme (Lorenzi et al., 2004). A further step would be to identify how such patients perceive their breathlessness and how it is affecting their lives.

## The handheld fan

A hand-held fan is a simple, manageable aid to relieving breathlessness for individuals suffering from dyspnoea. It is practical, cheap and easy to use at home or out and about, and does not have adverse side effects (Booth et al., 2008). An intervention that the individual can initiate at a time of their choosing and manage themselves promotes self-efficacy, something important to this group given that severe breathlessness is not easily controllable (Carrieri-Kohlman, 2006).

It has been reported that for the individual using the fan, a flow of air to the face, nasal mucosa, or pharynx may alter ventilation and relieve breathlessness (Schwartzstein, Lahive, Pope, Weinberger, & Weiss, 1987).

A randomised controlled crossover trial praised the benefits of the handheld fan supporting the hypothesis that a handheld fan directed at the face can reduce the sensation of breathlessness (Galbraith, Fagan, Perkins, Lynch, & Booth, 2010). Patients perceive the fan as one of the most important treatment strategies for the management of refractory breathlessness (Booth et al., 2014).

One study withheld a definitive conclusion on the efficacy of the handheld fan (Bausewein, Booth, Gysels, Haberland, et al., 2010), but given the distress patients suffer, and the positive reports from literature, it seems worth considering a simple, inexpensive intervention that has no ill effects and might reduce suffering (Galbraith et al., 2010).

In the current published literature, no large clinical trials have yet examined the use of handheld fans for the relief of breathlessness in patients (Marciniuk et al., 2011; Parshall et al., 2012).

## **Pharmacological treatment**

Studies investigating the use of pharmacological treatment such as opioids, oxygen and anxiolytics have published promising findings (A. Abernethy et al., 2003; Booth et al., 2008; Ferreira et al., 2016; Martins et al., 2016). It is reported that currently limited evidence

supports the routine use of a number of pharmacological drugs such as: benzodiazepines, antidepressants, phenothiazines and inhaled furosemide (S. Simon & Bausewein, 2009). Oxygen and opioids have more substantial research and are elaborated below.

### Oxygen

Booth et al. published an influential paper showing both cylinder oxygen and cylinder air can significantly improve breathlessness for hospice patients suffering from cancer (Booth, Kelly, Cox, Adams, & Guz, 1996). Abernethy et al. studied the use of oxygen vs. room air via a concentrator using a nasal cannula, at a rate of 2L per minute for a minimum of 7 days. The results suggested that patients found symptomatic relief from both methods, but with no significant differences between them (Abernethy et al., 2010).

Interestingly, in the evidence-based management guidelines from The Royal Australian College of General Practitioners (RACGP), oxygen therapy does not have sufficient support. The guidelines acknowledge it is widely used for dyspnoea but note that this is often with little reference to the individual's partial pressure of oxygen or pulse oximetry (Wiseman et al., 2013).

### Opioids

The use of oral morphine administered on sustained release at low dosage provides significant symptomatic improvement in refractory dyspnoea in a community setting, supporting individuals in their general struggle with dyspnoea as well as bringing improvements around quality of sleep (A. P. Abernethy et al., 2003). It is also reported that opioid use in breathlessness is most effective in management of non-malignant disease (A. Abernethy et al., 2003; Jennings, Davies, Higgins, Gibbs, & Broadley, 2002). The study by Abernethy et al. has significant rigour as a randomised, double blind, placebo controlled crossover trial. The only negative reported association were the side effects from the morphine that some participants found challenging, including severe constipation. However the study notes it was not empowered to address side effects. The above studies note the need to explore further *how* treatment outcomes make a difference to individual experiences of breathlessness.

## **Refractory breathlessness vs. pain**

After pain, refractory breathlessness is reported as the second most common symptom in patients with advanced chronic disease (Higginson et al., 2014). Like pain, refractory breathlessness is an experience arising from complex, non-static interactions between emotional, physiological and pathological elements (Higginson et al., 2014).

Therapeutic advances in the clinical management are limited and refractory breathlessness remains difficult to treat successfully, especially in advanced stages (Booth et al., 2008; Davidson & Currow, 2010). However, as reported by Currow et al. patients' access to adequate pain relief is now accepted as a human right. Given the burden of refractory breathlessness globally, the symptomatic treatment of this condition should be seen in exactly the same way as pain (Currow et al., 2016).

In addition, palliative patients, particularly with COPD, can benefit from better management of breathlessness, including improved pain management (Solano, Gomes, & Higginson, 2006). This suggests that in cases of prognostic uncertainty, palliative care should be made available on the basis of need assessed on the presenting symptoms, rather than on prognosis only (Solano et al., 2006).

## **Refractory breathlessness in a breathlessness clinic setting**

Studies have shown breathlessness clinics offer significant benefits in supporting individuals with severe breathing difficulties from an underlying chronic condition. For example, a newly established clinic specifically for lung cancer patients measured the benefits of the support they offered. The study produced very promising results when the percentage of patients experiencing breathlessness several times or more per day was reduced from 73% to 27% four weeks later (Hatley, Laurence, Scott, Baker, & Thomas, 2003). Beyond physical improvements, the study demonstrated significant improvements in quality of life with patients being freer to do more of the things they wanted (Hatley et al., 2003).

This clinic was led by a senior physiotherapist experienced in chronic dyspnoea management. Interventions offered during this study were very positively received. Interventions offered

over a period of 4-6 weeks included breathing retraining, basic relaxation techniques, activity pacing and psychosocial support. The success of this 2003 study by Hatley et al. mirrored two previously reported successful studies (Bredin et al., 1999; Corner, Plant, A'Hern, & Bailey, 1996), emphasising the benefits of a breathlessness clinic with significant breakthroughs in the management of dyspnoea both in regard to symptom control and improvements in psychological wellbeing. It's noteworthy to mention all three studies focused on lung cancer.

Similar results were seen in a randomised controlled trial by Higginson et al (2014) which looked at the experiences of patients with advanced disease and refractory breathlessness, comparing those receiving support through a breathlessness clinic with those receiving more usual care. Results suggested that patients did benefit from a dedicated palliative care breathlessness clinic setting. Benefits included improved management, decreased fear, anxiety, worry and panic, and greater confidence (Farquhar et al., 2014; Hatley et al., 2003). A bottom line benefit also found breathlessness clinic settings reduced the care costs of patients compared to standard care (Farquhar et al., 2014).

Studies have found breathlessness support services aim to provide patients with strategies and interventions to help them master their breathlessness, while accepting that the disease cannot be cured (Bredin, 1999; Corner et al., 1996; Hatley et al., 2003; Higginson et al., 2014). Thus, the amount of perceived breathlessness mastery is probably a more important component of quality of life than is the amount of actual breathlessness itself (Higginson et al., 2014).

### **Qualitative study methods for refractory dyspnoea palliative care patients**

When undertaking research with individuals suffering significantly on a daily basis, all measures need to be considered to ensure best possible practice is followed for the patients and for their carers. Undertaking research within a palliative care context can be challenging (Addington-Hall, 2002). Considerations include ethical, practical, methodological and emotional issues for potential participants, family and carers (Addington-Hall, 2002; Ewing et al., 2004). The ethical principles of the Declaration of Helsinki for human research ethics (World Medical Association, 2013) is the guiding cornerstone. As discussed, ethical approval has been granted for this study. Strict procedures have been followed to ensure this project is ethical, treating participants with unreserved respect and dignity.

The National Cancer Research Institute Palliative Care Breathlessness Subgroup supports qualitative study methods via unstructured or semi-structured interviews when researching breathlessness (Dorman et al., 2009). Furthermore, qualitative research gathering patients' and carers' experiences offers an extra dimension of understanding for a multi-disciplinary treating team (Dorman et al., 2009). Information such as this is not easily available via a quantitative study (Booth, Farquhar, Gysels, Bausewein, & Higginson, 2006; Booth et al., 2003).

Given the bleak prognosis of refractory breathlessness participants in any study, the potential to improve their remaining quality of life with evidence-based interventions and coping strategies (Booth et al., 2006) remains significant (Currow et al., 2016; Currow et al., 2010). This is particularly so in the context of management within a breathlessness clinic setting (Farquhar et al., 2014).

## **Conclusion**

In a 2010 Australian study, Davidson and Currow point to a significant disparity between the prevalence and severity of refractory dyspnoea and sufficient data to adequately inform evidence-based guidelines (Davidson & Currow, 2010). Those authors call for increased research to address the specific burden of refractory breathlessness symptoms.

Through an extensive review of the current literature of refractory breathlessness, it is clear that aspects of the pathophysiology, management and treatment have improved in recent times. However chronic refractory breathlessness remains significantly undertreated despite the prevalence, severity and chronicity of this symptom and an evidence base of affordable and safe interventions (Currow et al., 2014; Parshall et al., 2012).

As Currow et al. state, it should be a human right for patients with refractory breathlessness to be adequately treated (Currow et al., 2014). Pain control and management is now considered a human right (Brennan, Carr, & Cousins, 2007; Lohman, Schleifer, & Amon, 2010) The treatment of refractory breathlessness should be viewed and managed in the same way (Currow et al., 2016).

Studies linking refractory breathlessness with activities of daily living, including individual perspectives of daily activities and participation, are limited (Morgan & White, 2012), but it is

noted that people with advanced disease continue to strive for ongoing participation in everyday life to the best of their ability, irrespective of the profound symptoms of breathlessness they may be experiencing (la Cour, Johannessen, & Josephsson, 2009; Lyons, Orozovic, Davis, & Newman, 2002; Svidén, Tham, & Borell, 2010).

Further research exploring the experience of refractory breathlessness for individuals, how it affects their functional capacity and engagement in daily life, and where interventions would be most supportive, would be highly beneficial for those directly and indirectly affected, adding to the current body of literature.

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Ethical principles for medical research involving human subjects. *JAMA*, 310(20),  
2191-2194. doi:10.1001/jama.2013.281053

## **Section two: Journal Manuscript**

**Australian Occupational Therapy Journal title page requirements:**

(i) The Lived Experience of Refractory Breathlessness

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(iv) Experience of Refractory Breathlessness;

(v) Kezia Tieck was responsible for all data collection, lead the analysis and lead the compiling of the manuscript. Lynette Mackenzie contributed to data analysis. All authors contributed to writing the manuscript.

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(xiii) MeSH terms: dyspnea, occupational therapy, chronic obstructive pulmonary disease, activities of daily living, palliative care.



## **The Lived Experience of Refractory Breathlessness**

### **Abstract**

**Introduction:** Refractory breathlessness is breathlessness at rest or on minimal exertion that persists chronically even with optimal treatment of the underlying cause. Despite its burden and prevalence globally, symptoms remain under-treated and under-researched and those affected struggle daily with the condition.

**Aim:** The aim of the study was to gain a greater understanding of the lived experience of refractory breathlessness. Also, it was anticipated that a deeper insight into its impacts on daily activities would allow more effective occupational therapy interventions to be developed.

**Method:** A qualitative phenomenological approach using NVivo software, with one-on-one, semi-structured interviews and themes established through thematic analysis. The study recruited consecutive patients until thematic saturation was reached. Participants were recruited from a Sydney-based outpatient Breathlessness Clinic at a palliative care hospital.

**Results:** 6 participants were interviewed and 4 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, which describes the measures participants take to protect themselves from their own breathlessness. For each of the four themes, three to five subthemes were also identified through the analysis.

**Conclusion:** Of the 4 themes identified in this study, number 3 and 4 may represent the best targets for occupational therapy interventions. Patients noted the importance of functional participation for improved engagement and quality of life. There is scope to develop specific

interventions for self management and equipment prescription given lack of published literature in this area.

**MeSH terms:** dyspnea, occupational therapy, chronic obstructive pulmonary disease, activities of daily living, palliative care.

## **Background**

Breathlessness, also known as dyspnoea, is commonly associated with advanced chronic disease and is significantly debilitating (Currow et al., 2014). Breathlessness occurs in up to 94% of people with advanced Chronic Obstructive Pulmonary Disease (COPD) and 70% of patients with lung cancer (Blinderman, Homel, Andrew Billings, Tennstedt, & Portenoy, 2009; Currow et al., 2010; Solano et al., 2006). As the underlying disease progresses, the severity of breathlessness also increases, causing considerable distress and feelings of panic for people with breathlessness and their families (Higginson et al., 2014; Seow et al., 2011).

Breathlessness has a significant impact on individuals and their carers but is likely to be experienced differently due to a number of factors including the underlying diagnosis and disease progression (Currow et al., 2010; M. Gysels & Higginson, 2011). The cause of breathlessness will also influence its management and intervention (A. Abernethy et al., 2003; Currow et al., 2010)

Refractory breathlessness is the most crippling form, and is characterised as “breathlessness at rest or on minimal exertion that will persist chronically despite optimal treatment of the underlying cause(s)” (Currow et al., 2014). Refractory breathlessness patients have a variety of fluctuating emotional, physiological and pathological factors that require considerable management, in some cases in a palliative care setting. (Higginson et al., 2014).

Given its burden and prevalence globally, the symptoms of chronic refractory breathlessness remain under-treated and individuals may feel they have to accept it as part of their disease, despite an evidence base for management (Currow et al., 2014). Studies investigating the use of pharmacological treatment such as opioids, oxygen and anxiolytics have published success

(A. Abernethy et al., 2003; Booth et al., 2008; Ferreira et al., 2016; Martins et al., 2016).

These studies note the need to explore further how treatment outcomes have made a difference to individual experiences of breathlessness.

As management of refractory breathlessness is best done with a combined non-pharmacological and pharmacological interventions approach (S. Simon & Bausewein, 2009), further investigation of the potential contributions of allied health professional interventions such as occupational therapy is needed. Examples of studies linking refractory breathlessness with activities of daily living, including individual perspectives of daily activities and participation, are limited (Morgan & White, 2012).

The implications and the experiences of refractory breathlessness are currently under-studied and also present as an unmet palliative care need (Currow et al., 2016; Currow et al., 2010; Dorman et al., 2009; Maddocks et al., 2014). This is despite COPD being a major cause of refractory breathlessness. COPD is also a leading cause of death and disease burden (after heart disease, stroke and cancer) in Australia (Lung Foundation Australia, 2012), and is the second leading cause of avoidable hospital admissions (Glover et al., 2007).

Therefore, this study aims to contribute to a better understanding of the experience of refractory breathlessness from the perspective of people experiencing it. This will allow further insight into the impacts of refractory breathlessness on daily activities and more effective interventions to be considered, including those around daily occupations.

## **Methodology**

### **Ethics**

This study was conducted in a partnership between the University of Sydney and HammondCare Greenwich Hospital.

The research project was granted ethical approval (LNR/17HAWKE/154) from NSW Health through the Northern Sydney Local Health District (NSLHD) research office Human Research Ethics Committee (HREC) and the HammondCare Research Governance Body and HammondCare Steering Committee. Patients were provided with an information and consent form prior to participation in the study and were required to provide written and verbal consent prior to interview.

### **Study design**

This exploratory qualitative study used a phenomenological approach (Lindseth & Norberg, 2004) focusing on a personal lived experience (Polgar & Thomas, 2013) of refractory breathlessness. A phenomenological approach allows an understanding of the meaning of a phenomenon within the unique experience of participants. This study focused on the individual experience of refractory breathlessness and how it affects the everyday lives of study participants.

## **Participants**

Participants were recruited by the medical team at the HammondCare Breathlessness Clinic and verbally offered the opportunity to participate in the study. Patients were informed that their decision to participate would not affect their care from the Clinic.

The target population for this study were men and women living with refractory breathlessness. The inclusion, exclusion and withdrawal criteria were as follows:

### Inclusion Criteria

- Diagnosis of refractory breathlessness by the Breathlessness Clinic.
- Over 18 years of age
- Able to converse in English
- Able to independently attend the Clinic at Greenwich Hospital and considered fit to participate in an interview by medical staff

### Exclusion Criteria

- Unable to converse in English
- Medically excluded by staff at Greenwich Hospital

### Withdrawal Criteria

- Participant choice
- Symptoms becoming too severe

The study was reliant on the numbers of patients being treated at the Breathlessness Clinic during the recruitment phase of the study.

## **Data collection**

Four participants were interviewed at the Breathlessness Clinic, Greenwich Hospital, and the remaining two were interviewed in their homes, due to an exacerbation of symptoms and inability to travel easily. The interviews took place between July and September 2017, were face-to-face semi-structured, lasting between 29 and 39 minutes using an interview schedule. Interview topics covered areas such as diagnosis and disease progression, experience of breathlessness, typical day description, activity participation, rest and sleep, carer support and social relationships, spiritual support and self-care, and how they manage their breathlessness at this stage in their disease progression.

All participants had refractory breathlessness and some had difficulty talking, therefore time was taken to accommodate their needs individually. The interviews were voice recorded and transcribed verbatim, with additional observations and field notes recorded. The purpose of the interviews was to gain each individual's perspective on how refractory breathlessness affects their everyday life. The interviewer explored how the breathlessness affected different areas of each person's life.

## **Data analysis**

The aim of the thematic analysis was to gain greater understanding and interpretation of the lived experience of the participants (Polgar & Thomas, 2013),

Two-stage coding was used to analyse the data (Saldaña, 2012). The first stage summarised segments of data line by line. The second stage grouped the findings into fewer categories to analyse and establish clear themes and sub themes with consensus cross checking. Nvivo software was used to manage the data.

## **Results**

A total of six participants were recruited and interviewed until thematic saturation was achieved, as summarised in Table 1. Participants presented at their individual interviews with varying levels of breathlessness. Some were concerned about their capacity to participate and required specific details of the location of the interview room to determine if they could manage the walking distance and the possible effect on their breathlessness. Participants were all offered explicit opportunities to take a break whenever they needed it in order to calm their breathing.

Four main themes and fifteen subthemes were established from the thematic data analysis, outlined in table 2.

### **Theme 1: Living on the edge**

All participants described some level of how precarious their overall life situations were because of their breathlessness. This was expressed in relationship to the immediacy of feeling breathless. For instance, one participant stated:

*“When you can't breathe, nothing else matters.” (P3)*



This poignant statement expresses the feelings accompanying breathlessness and demonstrates the profound impact on quality of life because of it. Participants feel they are living on the edge, consumed and controlled by their breathlessness and the limitations it causes in their lives.

### **Experiences of not being able to breathe**

Some participants (identified here by Participant number, as P1- P6) described feeling as though they were being deprived of breath to the point they may not survive being seriously breathless. They also described the fear associated with panicked breathlessness and the vicious cycle it triggers of being unable to catch their breath:

*“Sometimes you feel like you are suffocating.” (P6)*

*“When it gets bad enough, I feel that I'm not going to get enough air and I'm going to die.” (P2)*

*“You can't breathe deep enough.” (P3)*

While participants described their breathlessness individually, a common theme was of feeling they were living in a heightened state of awareness around their inability to comfortably take a breath.

Participant 4 described his breathlessness as a totally overwhelming experience that can come over him simply by doing a basic activity such as trying to walk 30m to his vehicle:

*“Just an extreme case of breathlessness. I lose all my strength and I become very breathless.” (P4)*

Participant 6 indicated that it would be hard to let anyone else know about her distress when breathless:

*“I can't even get through a sentence without huffing and puffing.” (P6)*

### **Adapting to breathlessness**

To function day to day, participants made changes in their lives to manage their breathlessness. This required a lot of thinking about alternatives and learning from experience how to preserve a way of living that was at least somewhat satisfying or sustainable. Each person adapted in different ways based on their personal health, social support and living circumstances. Doing things slowly was a common strategy. For instance:

*“There's a great deal of learning involved once one develops this sort of thing [breathlessness] because one wants to learn what is the best way of living with it and still having some sort of life. So I've learned to do things slowly, for example.” (P5)*

*“I have to really do everything slowly, I mean, I might get my underwear on and a pair of pants or something and then I've got to stop and breathe.” (P2)*

### **Frustration with breathlessness**

Five of the six participants expressed frustration around their breathlessness and the limitations that come with it. Many talked about being debilitated by their condition that prevented them from engaging in occupations they enjoyed or were important. For example,

they spoke of feeling very frustrated because they can't do simple tasks such as walking to their car without becoming breathless. They also noted the frustration associated with the inability to plan an outing with friends without needing to know all the details in case factors would make their breathlessness worse.

*"I just feel really teed off that I have got this problem even though I realise it's mine, my fault. I've always been extremely fit, outdoors sort of a person and now I'm limited." (P1)*

*"I am sort of almost angry that I'm in this situation." (P1)*

One participant stated that she couldn't afford to get frustrated because it made things worse, so she denied her frustration:

*"No, because I very deliberately don't let it ... Because if I became frustrated I would become breathless." (P5)*

This statement indicated her awareness of the potential for frustration. It also expressed her efforts for self-preservation and her need to maintain some control in her situation despite the restrictive reality of her breathlessness.

## **Theme 2: Social Needs and Support**

Social support was a significant factor for a number of participants managing their underlying disease as well as breathlessness. They described how much they rely on their family or partner for daily support, and also their fear as to what they would do if they didn't have this support in place helping them cope. This was expressed by all participants, except one. The

sole participant living alone and not in a relationship viewed her social support needs differently. She felt comfortable on her own because she didn't need to consider anyone else's needs:

*“Because I'm virtually on my own I think, in a way, although it's sort of lonelier for company, but I've more freedom in that I don't have to accommodate someone else.”*

*(P3)*

Social support was, however, seen by the other participants as vital for those unable to do daily self-care tasks easily and freely. Some participants reflected on what care they might be receiving if they didn't have a supportive family. For instance:

*“If I didn't have family support I doubt ... I mean I'd have to be in some sort of assisted place anyway.” (P4)*

### **Pragmatics of getting out**

Participants described the planning and practical considerations of leaving the house, and how these had become increasingly difficult as they attempted to manage their breathlessness. Essential medical appointments were mentioned as a necessity but difficult to plan and attend at times due to the physical burden of their breathlessness.

*“So medical appointments ... Well actually, yes, it has been a pest at times, thinking I probably need to go to the GP but it'll be a bit awkward getting there, even in the car, because I'm breathless.” (P5)*

Social outings were planned based on several factors including familiarity of location that offered predictability when considering walking distance, parking ease, waiting time and the physical environment. These considerations limited the choices participants made, for instance:

*“...we have to discuss whether there's stairs, how far I have to walk, um, all this has to be done before I can even think about saying yes to anything.” (P2)*

A number of participants relied on their social support networks to drive them to appointments, social engagements and to access the community. This support assisted those participants to actually leave their home which for some was a significant event. Some described a physical struggle leaving the house that was sometimes impossible without help.

For one participant, even small distances are a challenge:

*“Just getting from the house to the car, I have to stop usually twice before I can get to the car. Sometimes I get down the stairs and then I've got to rest on the bloody bin to breathe.” (P2)*

This 20-metre walk from her front door to her car caused significant breathlessness and was an on-going struggle each time she went out.

Another participant described how his declining health meant that he had lost the desire to socialise. The idea of trying to go out was unappealing due to logistical considerations

because his physical limitations were becoming more difficult. He felt it was easier just to stay at home, despite the risk of social isolation:

*“You just don't feel like socialising too much any more you know, and it's because of all those things you know you have to think of distance, walking, and, you know, get uncomfortable even sitting down in the one spot, so there's all these things that will affect your mood and your lifestyle definitely. It has an enormous impact. It's easier just to stay at home.” (P4)*

*“I have no real social life any more.” (P2)*

### **Effect of breathlessness on relationship with others**

Refractory breathlessness not only affects the patient but also those around them. Watching a loved one gasp for breath was described as distressing for her partner by one participant. She felt her condition was a dreadful thing to witness:

*“He's seen me in extremis and panting a bit, so it must be ghastly. I mean, it's nasty putting up with it, but it must be pretty terrible looking at somebody.” (P5)*

Having a supportive relationship was mentioned as a coping strategy. One participant, however, described how her husband didn't understand her breathlessness. This clearly was very distressing for her and his lack of understanding had a negative effect on their relationship.

*“I think he's in denial. He doesn't feel I'm all that sick... He feels that I'm getting lazy... He gets cranky and agitated easily with me if I walk from one [place] to the next and I have to stop. He gets annoyed.” (P2)*

While all participants spoke openly during interviews, one disclosed how she consciously chose to protect her privacy around her condition from friends and family, aside from her husband. She does not share details of her severe COPD, instead referring to it as “this bloody chest thing”. (P5)

### **Theme 3: Reduced to the basics**

Participant 4 described his current activity capacity as reduced to “*just the basics of life*”. He is so unwell and breathless the activities he used to do such as paid work, mowing, socialising or driving are now impossible. He feels defeated that he has such a reduced capacity and how it affects all aspects of his life.

*“If you can't breathe, you can't walk, you can't do anything. You can't swim, or ... All the things you'd like to do, you can't do them anymore.” (P4)*

### **Adjusted capabilities**

To maintain meaningful participation in even basic activities, participants had to adjust their personal expectations of what they could achieve. They needed to come to terms with their reduced capacity and what they could expect of themselves, or what meaningful occupations they could participate in. Participants reflected on what they had lost as a result of their breathlessness. For instance:

*“I’ve always been extremely fit, outdoors sort of a person and now I’m limited.” (P1).*

One participant described that adjusting to their capabilities meant that they experienced breathlessness without gaining anything or without any participation:

*“And that is really so, so, so overwhelming because you're gasping for breath over [doing] nothing.” (P3)*

### **Capacity to undertake Activities of Daily Living (ADLs)**

The breathlessness experienced by participants affected basic ADL activities.

*“Even though I've been on oxygen all night, I'm breathless as soon as I get up to go to the toilet.” (P2)*

*“So I sit on the toilet to do on my breathing technique before I can go any further to help me through that.” (P2)*

Activities that were limited included cleaning, dressing, showering and using the toilet.

*“Showering and dressing are a real, a real task, yeah.” (P2)*

*“I have to really do everything slowly, I mean, I might get my underwear on and a pair of pants or something and then I've got to stop and breathe.” (P2)*

Participants described their struggles but also their initiatives to adapt, pace themselves or use breathing techniques and self-talk to cope with their reduced capacities and try to meet their



basic care needs. Patients mentioned sitting to dress, cleaning for 10-minute bursts and slowing the pace of tasks down to accommodate their breathlessness.

*" So I've got to do the cleaning over a few days" (P3)*

*"I get a few steps and I've got to sit. And I just feel it's not worth it. I try to push myself, but it's just not happening." (P2)*

(Self talk) *"Hey [participant name], do the proper sort of breathing- 'in': smell the roses and blow out over the sea." (P1)*

### **Psychological distress**

Participants openly spoke about their growing realisation that their daily lives were more difficult because of their refractory breathlessness and the psychological toll this has on them. Emotions and psychological impact were expressed differently by all participants but each voiced negative associations with the condition. For instance:

*"I have always been a happy person, but I think I am probably less happy now." (P1)*

Participant 5 described panic when experiencing breathlessness:

*"Once you panic, you panic more, and then you become more breathless so you panic more. Ghastly. Truly ghastly." (P5)*

### **Pacing**

A number of participants spoke about the need to pace their level of activity to manage basic tasks. They also discussed their worries about over-exerting themselves, then causing

breathlessness that could lead to panic, making it worse. This meant adapting to not being able to do things at their previous “normal” pace. For instance:

*“But if I did things at my normal pace, what used to be my normal pace, I would get breathless, and then the worst thing is to panic.” (P5)*

There were consequences for the participants if they did not pace themselves to meet their capacity level for activity:

*“There are a lot of things I can't do. And I'm aware that if I move too quickly I'm likely to become more breathless.” (P5)*

*“I end up doing things and then I get really puffed and think oh, I forgot, I'm supposed to have a rest.” (P6)*

## **Sleep and rest**

Varied responses around sleep were reported. A number of participants had sleeping limitations such as sleeping positioning and perceived poor quality of sleep. Several reported that they sleep propped up with pillows or sitting up on a sofa to prevent breathing difficulties. Some report taking pharmacological drugs such as OxyNorm with sleeping tablets or Panadeine Forte to aid restful sleeping. Positioning was mentioned a number of times to ease the struggle to sleep.

*“Sometimes during the night if I sleep, I sort of sit, sleep, semi-sitting up.” (P4)*

*“And it didn't matter what I took, um, nothing helped the pain and a girlfriend gave me a Panadeine Forte and one night I took it and it was the best sleep ever.” (P6)*

*“I've got to sit up on five pillows to sleep. And that's horrible.” (P3)*

#### **Theme 4: Sources of security**

A number of the participants used interventions, equipment or limited themselves to familiar settings to offer security to manage their breathlessness. Their need to have some security in case they became more breathless influenced their actions and decisions.

##### **Handheld fan**

One participant described his handheld fan as *“just incredible” (P1)*. So much so, that he preferred to rely on this rather than his home oxygen supply when he felt breathless. It gave him confidence to help manage his breathlessness.

Another patient anticipated the benefits of using a handheld fan due to its mobility and convenience:

*“I think it [the handheld fan], makes me ultimately a bit more mobile, just from having confidence that I'll know if I get breathless I can whip out a little thing and get a blast of cold air on my face.” (P5)*

This participant perceived that the handheld fan would enable her to be more mobile and offered her added security that she would be able to get her breath back if she became breathless.

### **Equipment to help with coping**

Certain types of equipment offered a way of coping for the participants: portable oxygen, home oxygen, CPAP machine, face masks, or a long-handled reacher. One participant spoke about the certainty of knowing oxygen was available at venues should it be required. Another mentioned keeping portable oxygen in her car to offer reassurance if she needs it. She said:

*“I don't think I need it but I'm too scared to give it up just in case, it's a security.”*  
(P6)

The use of a face mask in public allowed participants to reduce the risk of infection, particularly in crowded places or when coughs and colds become more prevalent. For instance:

*“Better I be sort of protected than copping someone's germs because when I'm sick, I'm sick for, say, like three weeks, sitting up, just to sleep.”* (P3)

### **Feelings of security influencing social outings**

Participants reflected that having familiar measures in place acts as a source of security when they are out in public. One woman described knowing that trained staff at a frequently visited venue could help if medical treatment was needed. That offered her peace of mind. She has not required that help, but knowing it is available was reassuring. This patient also mentioned that the distance to the hospital from the venue was closer than from her home. These details gave her “*comfort*” (P2).

Comforting or encouraging self-talk seems to offer some protection against the increasing powerlessness of refractory breathlessness.

## **Discussion**

Individual personal experiences of refractory breathlessness are not well studied, particularly from an allied health occupational therapy perspective that focuses on enabling participation in everyday activities to the best of the individual's abilities (Morgan & White, 2012). The purpose of this study was to investigate the experience of refractory breathlessness from individuals' own perspectives and to describe how they perceived this affected their daily lives. The results of this study show that refractory breathlessness significantly impacts the daily lives of participants and their families, including physical capacity, mood, sleep, routine, social contact and feelings of security and, in turn, the functional capacity of individuals which has a significant effect on participation and quality of life.

The themes identified clearly indicated the severe limitations refractory breathlessness brings. Similar themes have been explored in studies of individuals with COPD and heart failure. Findings included the perception and severity of breathlessness and the accompanying fear, panic and anxiety it generated (Barnett, 2005b). Living in fear of their disease was also highlighted in a study examining the experience of people with heart failure (Ryan & Farrelly, 2009), noting the profound impact this had on participation in daily life.

Of particular importance to occupational therapy are themes 3 and 4 which deal with functional and psychological limitations of refractory breathlessness on quality of life and activities of daily living.

These themes have also been highlighted by other research groups. One study noted that as the disease progresses with COPD patients, basic daily tasks become harder (Barnett, 2005a). The use of assistive devices such as home oxygen were mentioned as an important resource by this group but findings are mixed with a study by (Ek, Sahlberg-Blom, Andershed, & Ternstedt, 2011) noting that while home oxygen assists with relieving breathing difficulties it can also be a limitation. Some patients could not mobilise the tank independently, making them more inclined to stay home, risking isolation. One participant in this study requiring home oxygenation expressed this concern.

The goal for people with refractory dyspnoea is not curative but rather to increase their levels of control over their condition and functional engagement. This improves their confidence and self-worth through participation in daily life. Participants in our study have all independently initiated or learned self-management behaviours from the Breathlessness Clinic such as adapting activities, pacing, self-talk, and utilising social support. These behaviours have been previously reported for patients with chronic respiratory illness (Apps et al., 2014). Pacing, for example, has been described as a beneficial adaptation to conserve energy, enabling more effective participation in daily activities (Apps et al., 2014). The benefits in self-management of chronic disease reflect the Australian Government's *Sharing Health Care Initiative*. This includes positive psychological and physical benefits from increasing the knowledge base of people with this condition, supporting self-efficacy and physical activity (Australian Government, 2005). Self-management and self-management support are key aspects of optimal chronic disease care based on research in self-care programs (Glasgow, Jeon, Kraus, & Pearce-Brown, 2008).

This study showed that small equipment implementation can make a significant difference in feelings of comfort and self-management. For example, the use of a handheld fan was praised

in this study and reinforced in a randomized controlled crossover trial (Galbraith et al., 2010). Use of this inexpensive, non-invasive and patient-directed device, pointed at the face, reduces the sensation of breathlessness and is recommended in palliative care management (Galbraith et al., 2010). One study was unable to conclusively prove the benefit of a handheld fan (Bausewein, Booth, Gysels, Kühnbach, & Higginson, 2010). However, given that an intervention like this might reduce individual's experience of breathlessness and has no ill effects, it should be considered given the distress patients suffer and the positive reports, including from participants in this study.

The seriousness of each person's reported experience supports the argument that further research is needed to reduce what Chin, & Booth (2016) call the unnecessary suffering that refractory breathlessness brings when it is inadequately managed. They point to the potentials of a genuinely multi-disciplinary approach to evaluate both the science and the delivery of services to sufferers, including a deeper understanding of the meaning of breathlessness for those living with it.

Studies suggest that the most effective treatment path for refractory breathlessness is a combination of pharmacological and non-pharmacological approaches (Bausewein, Jolley, Reilly, Lobo, Kelly, Bellas, Madan, Panell, Brink, De Biase, Gao, Murphy, McCrone, Moxham, et al., 2012; Chin & Booth, 2016; S. Simon & Bausewein, 2009). Progress has been made in identifying the links between pathophysiology and the origin of breathlessness, as well as pharmacological treatment – particularly opioids and non-pharmacological interventions (Davidson & Currow, 2010; Johnson, Abernethy, & Currow, 2012).

An occupational therapy perspective brings an opportunity to support this group with better self-management, intervention and coping strategies. It takes into account individual circumstances and needs so each patient may be less fearful and better supported to experience the best quality of life accessible to them at their stage of illness (Morgan & White, 2012).

Given its prevalence and the severity of symptoms, refractory breathlessness is deserving of ongoing research in all aspects (Davidson & Currow, 2010). Adequate and individualised understanding and support are called for. Building on the non-pharmacological contributions to more effective patient support, occupational therapy research in palliative care already shows that through functional participation in everyday activities (such as those discussed in this study), individuals can more effectively maintain a sense of self and control over their changing physical self (Davidson & Currow, 2010; Mattingly & Fleming, 1994; Morgan & White, 2012).

Limitations of this study included the small study size and all study participants coming from the Sydney metropolitan area. The small study size was anticipated by the distressing nature of the illness and disease progression and sourcing participants from a single Sydney clinic, influencing their experience of their illness. Importantly however, data saturation was reached in this study even with a relatively small sample size. Interviewees repeated consistent themes, particularly around self-management behaviours for their breathlessness and how this symptom limits their lives. A larger sample with multi-centre recruitment could enable a more comprehensive analysis. The non-responders in this study may have been individuals whose physical or psychological distress or illness progression made them unable to participate, which may mean that the findings from this study have under-estimated the distress experienced by participants.



## **Conclusion**

This study identified four key themes, two of which, namely Reduced to the Basics and Sources of Security may be particularly well suited towards occupational therapy interventions. Participants noted the importance of functional participation for improved engagement and quality of life for individuals suffering from refractory breathlessness. Our literature review research found limited studies regarding specific interventions for self management and for equipment prescription, supporting the need for further research.

## **Key Points for Occupational Therapy**

- The functional and psychological consequences of refractory breathlessness impair individuals' quality of life and activities of daily living.
- Occupational therapists have a role in improving individuals' experience with refractory breathlessness, through equipment prescription and teaching of self-management techniques.
- A handheld fan can empower and promote self-efficacy for patients.

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## **Tables**

Table 1: Demographic characteristics of participants (n=6)

Table 2: Themes and sub themes

**Table 1: Demographic characteristics of participants (n=6)**

	Sex	Age	Marital status	Aetiology
Participant 1 (P1)	M	86	De facto	COPD
Participant 2 (P2)	F	63	Married	COPD
Participant 3 (P3)	F	71	Single	Lung Cancer
Participant 4 (P4)	M	69	Married	Heart Failure
Participant 5 (P5)	F	67	Married	COPD
Participant 6 (P6)	F	54	Single	Metastatic Breast Cancer

**Table 2: Themes and sub themes**

<b>Main Themes</b>	<b>Subthemes</b>				
<b>Living on the edge</b>	Reality of breathlessness	Experiences of not being able to breathe	Adapting to breathlessness	Frustration with breathlessness	
<b>Social Needs and Support</b>	Social support is vital	Pragmatics of getting out and about	Effect of breathlessness on relationships with others		
<b>Reduced to the Basics</b>	Adjusted capabilities	Capacity to undertake Activities of Daily Living (ADLs)	Psychological distress	Sleep and rest	Pacing
<b>Sources of security</b>	Hand held fan	Equipment to help with coping	Feelings of security		

## **Appendices**

Ethical approval letter from NSW Health

Ethical approval letter from Greenwich Hospital

NSW Health approved participant information sheet and consent form

Interview schedule

Literature search strategy

ICF Model application to refractory breathlessness

Australian Occupational Therapy Journal Guidelines

# Ethical approval letter - NSW Health

Research Office  
Kolling Building, Level 13  
Royal North Shore Hospital  
St Leonards NSW 2065  
Tel (02) 9926 4590 Fax (02) 9926 6179



1 June 2017

A/Prof Lynette Mackenzie  
University of Sydney  
75 East Street  
Lidcombe NSW 2141

Dear Lynette,

**NSLHD reference: RESP/17/123**  
**Study Title: The Experience of Refractory Breathlessness on Everyday Life**  
**HREC reference: LNR/17/HAWKE/154**

Thank you for submitting a response, dated **11 May 2017**, to the Northern Sydney Local Health District HREC Executive Committee's request for additional information/modification of the above study, which was first considered at a meeting of the HREC Executive held **1 May 2017**. Based on the information you have provided and in accordance with the NHMRC National Statement 2007 and NSW Health Policy Directive PD2010\_055 Ethical and Scientific Review of Human Research in NSW Public Health Organisations, this project has been assessed as low/negligible risk and is therefore exempt from full HREC review.

This HREC has been accredited by NSW Ministry of Health as a Lead HREC under the model for single ethical and scientific review and Certified by the NHMRC under the National model for Harmonisation of Multicentre Ethical Review (HoMER). This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. No HREC members with a conflict of interest were present for review of this project.

I am pleased to advise that the HREC, at a meeting of its Executive Committee held on **24 May 2017** has granted ethical and scientific approval of the above **single centre** project. The HREC have determined that this project meets the requirements of the National Statement.

**You are reminded that this letter constitutes *ETHICAL* and *SCIENTIFIC* approval only. You must not commence this research project at a site until a completed Site Specific Assessment Form and associated documentation have been submitted to the site Research Governance Officer and Authorised. A copy of this letter must be forwarded to all site investigators for submission to the relevant Research Governance Officer.**

The project is approved to be conducted at

- **Greenwich Hospital**

If a new site(s) is to be added please inform the HREC in writing and submit a Site Specific Assessment Form (SSA) to the Research Governance Officer at the new site.

The following documents have been approved:

Document	Version	Date
Protocol	1	18 April 2017
Participant Information Sheet and Consent Form	2	11 May 2017
Interview Questions	1	18 April 2017

The Low and Negligible Risk Research Form reviewed by the HREC was **LNR AU/6/8C5D211**.

Please note the following conditions of approval:

- HREC approval is valid for **5 years** from the date of the HREC Executive Committee meeting and expires on **24 May 2022**. The Co-ordinating Investigator is required to notify the HREC 6 months prior to this date if



the project is expected to extend beyond the original approval date at which time the HREC will advise of the requirements for ongoing approval of the study.

- The Co-ordinating Investigator will provide an annual progress report to the Institution beginning in **August 2017** as well as a final study report at the completion of the project using the template available on the Research Office website. An annual report is due **every year on 30 August**.
- The Coordinating Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project and any complaints made by participants regarding the conduct of the project.
- Proposed changes to the research protocol, conduct of the research, or length of approval will be provided to the HREC Executive for review, in the specified format.
- The HREC Executive will be notified, giving reasons, if the project is discontinued before the expected date of completion.
- Investigators holding an academic appointment (including conjoint appointments) and students undertaking a project as part of a university course are advised to contact the relevant university HREC regarding any additional requirements for the project.

Should you have any queries about your project please contact the Research Office, ph: 9926 4590, email [NSLHD-Research@health.nsw.gov.au](mailto:NSLHD-Research@health.nsw.gov.au).

Please quote **NSLHD reference RESP/17/123** in all correspondence.

The HREC wishes you every success in your research.

Yours sincerely



**Monique Macara**  
*Research Ethics Manager*  
NORTHERN SYDNEY LOCAL HEALTH DISTRICT

cc. Kezia Tieck

RESD/17/3884

# Ethical approval letter - HammondCare Greenwich Hospital



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22<sup>nd</sup> May 2017

Associate Professor Lynette Mackenzie  
University of Sydney  
lynette.mackenzie@sydney.edu.au

Dear A/Prof Lynette Mackenzie,

**Project title:** The Experience of Refractory Breathlessness on Everyday Life  
**Project duration:** May 2017 to Nov 2017

Thank you for submitting a research project application form. I am pleased to inform you that HammondCare, at an organisational level, supports this proposal. Though please note that this letter does not constitute authorisation to commence research activities.

#### What's next?

- 1) Where applicable, please liaise with the manager of the site you will be conducting your research;
- 2) Your project has been allocated the following project code **R136**. Please use this identifier in all correspondence for this project;
- 3) If applicable, please email HC RGO the fully signed contract;
- 4) The site investigator is reminded that access to HammondCare data must be in accordance with HammondCare's policy, *Confidentiality of Resident and Client Information* and the *Privacy Act 1988* and all Non-HammondCare Researchers must sign and submit to the HammondCare Research Governance Office a *Privacy and Confidentiality undertaking [attached]*;
- 5) If Intellectual Property and data ownership is shared between investigators and/or multiple organisations please ensure there is a legal agreement (MOU) or other written document that defines this division;
- 6) Ethics review and approval and a site specific assessment must be undertaken prior to the commencement of research at any HammondCare site. Please refer to the Research Project Checklist/Tutorial on the intranet or on request via [rgo@hammond.com.au](mailto:rgo@hammond.com.au)
- 7) If the project has not commenced within six months, please contact the HammondCare RGO at the stage you resubmit this proposal to discuss resubmission options.

#### Preparing your participant documentation for ethics/governance submission:

- 1) Ensure your Participant Information Sheet includes a) the contact details of the HammondCare site investigator b) the contact details the HammondCare Research Governance Officer c) the contact details and reference number of the Human Research Ethics committee;

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9 Judd Avenue, Hammondville, NSW 2170

P +61 2 8788 3900 • F +61 2 9731 1235 • E [uniclinic.hammondville@hammond.com.au](mailto:uniclinic.hammondville@hammond.com.au) • [www.hammond.com.au](http://www.hammond.com.au)

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- 2) Ensure your Participant Information Sheet and Consent Form and any other participant documentation include the HammondCare logo and are site specific date and version controlled;
  - a. For example for H&H projects: PISCF Site Specific V1 August 20 2014 ([Braeside Hospital](#)) based on Master PISCF V1 July 20 2014
  - b. For example for non-hospital projects conducted in more than one facility you only need one site specific Participant Information Sheet to cover all sites: PISCF Site Specific V1 August 20 2014 ([HammondCare](#)) based on Master PISCF V1 July 20 2014
- 3) Provide a checkbox and address or email field on the consent form to enable participants to indicate if they want to receive a simple summary of the study findings on conclusion of research;
- 4) As it is assumed a significant number of participants will be older people it is advisable you increase the font size on your Participant Information Sheet, Consent Form and Withdrawal of Consent for easier readability.

If you have any queries don't hesitate to contact me on (02) 8788 3957 or [rgo@hammond.com.au](mailto:rgo@hammond.com.au).

Yours sincerely

Kristine Apitz  
Research Governance & Business  
cc Prof Chris Poulos & Prof Melanie Lovell

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# Ethical approval letter - HammondCare Greenwich Hospital Research

## Governance Body



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21 June 2016

Associate Professor Lynette Mackenzie  
University of Sydney  
lynette.mackenzie@sydney.edu.au

Dear A/Prof Lynette Mackenzie,

**Project title:** The Experience of Refractory Breathlessness on Everyday Life

**Project duration:** May 2017 to Nov 2017

The following documents are authorised for use.

Document	Version	Date
SSA_Form_kezia_Tieck	NA	NA
Scan SSA Signatures	NA	NA
NSLHD_PISCF_Interventional_Standard LM	2	11/5/17
Ethics approval letter	NA	24/5/17

I am pleased to inform you that authorisation has been granted for this study to take place at Greenwich Hospital subject to the individual consent of the prospective participants and the following requirements.

These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

**Additional conditions (where applicable):**

1. For any non-HammondCare researchers accessing a HammondCare site please email HammondCare Research Governance Officer [rgo@hammond.com.au](mailto:rgo@hammond.com.au) the following certificates:
  - a. an aged and vulnerable national criminal record certificate no older than 3 years,
  - b. a current public insurance indemnity certificate
  - c. a current professional insurance indemnity certificate
  - d. and a current workers compensation certificate
2. Please liaise with the site/facility manager(s) about commencing your project and clarify any site requirements;
3. If applicable, a list of required records must be provided to Health & Hospitals Data Manager Yoomee Oh ([yoh@hammond.com.au](mailto:yoh@hammond.com.au) tel: 02 9903 8350), at least 2 weeks prior to the intended date of record review if less than 50 records are required. If more than 50 records are required, please inform Yoomee at least 4 weeks in advance. On the day(s) of record review, Yoomee will assign a viewing room and will provide the requested records. All records must remain on

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HammondCare premises at all time. No photocopies of the medical records are permitted.

4. The site investigator is reminded that access to HammondCare data must be in accordance with HammondCare's policy, *Confidentiality of Resident and Client Information* and the *Privacy Act 1988*;
5. The site investigator is reminded that all data from this project must be retained securely for a period consistent with the prescriptions of the *Australian Code of the Responsible Conduct of Research*;
6. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, must be copied to the HammondCare Research Governance Officer;
7. Annual reports submitted to the lead HREC must be copied to the HammondCare Research Governance Officer;
8. The HammondCare Research Governance Officer must be notified of changes to the status of the study including whether it is temporarily halted, completed, terminated, suspended, restarted or abandoned.

If you have any queries don't hesitate to contact the HammondCare Research Governance Office via email [rgo@hammond.com.au](mailto:rgo@hammond.com.au) or phone 02 8788 3957.

Yours sincerely

Kristine Apitz  
Research Governance & Business  
cc Prof Chris Poulos & Prof Melanie Lovell

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# NSW Health approved participant information sheet and consent form



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**The University of Sydney and HammondCare Greenwich Hospital**

## **PARTICIPANT INFORMATION SHEET AND CONSENT FORM**

for substitute consent make relevant throughout document

### **QUALITATIVE STUDY**

The Experience of Refractory Breathlessness on Everyday Life

#### **Invitation**

You are invited to participate in a research study about the experience of refractory breathlessness on everyday life, looking at how the breathlessness you experience affects regular daily activities. Findings from this study aims to improve understanding and care of breathlessness patients.

The study is being conducted by:

Professor Melanie Lovell

Senior Staff Specialist, Palliative Care

Medical Director, Greenwich Palliative and Supportive Care Services

Clinical Associate Professor, Sydney Medical School

Adjunct Professor, Faculty of Health, University of Technology Sydney

Associate Professor Lynette Mackenzie

Discipline of Occupational Therapy

Faculty of Health Sciences

The University of Sydney

Ms Kezia Tieck

Masters of Occupational Therapy student

Faculty of Health Science University of Sydney

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

#### **1. 'What is the purpose of this study?'**

The purpose is to investigate what the experience of refractory breathlessness in everyday life and how it affects your daily activities.

#### **2. 'Why have I been invited to participate in this study?'**

You are eligible to participate in this study because you are a patient in the Breathlessness Clinic at Greenwich Hospital.

**3. 'What if I don't want to take part in this study, or if I want to withdraw later?'**

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you.

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason.

**4. 'What does this study involve?'**

If you agree to participate in this study, first you will be asked to sign the Participant Consent Form. This study will be conducted during a pre-arranged interview time while you are visiting the Breathlessness Clinic. This involves a single face to face audio recorded interview that will take approximately 30 minutes. All interview questions will be given to you prior to the interview to give you a chance to think about your answers prior.

**5. 'How is this study being paid for?'**

This is a student project being conducted as part of a University of Sydney Masters of Occupational Therapy research project. The project is being supported by HammondCare Greenwich Hospital.

**6. 'What are the alternatives to participating in this study?'**

If you decide not to participate in this study, you will still receive the standard treatment available for your condition through the Breathlessness Clinic.

**7. 'Are there risks to me in taking part in this study?'**

As this is a single qualitative interview, no answer is wrong as it is your personal opinion and self-expression, risk is minimal. If you do not wish to answer a question you may skip it and move on to the next. If you suffer any distress as a result of participating in this study you should contact the study team who will assist you in arranging appropriate support.

**8. 'Will I benefit from the study?'**

This study aims to further our understanding of the experience of breathlessness and may improve future management of refractory breathlessness however it may not directly benefit you.

**9. 'Will taking part in this study cost me anything, and will I be paid?'**

Participation in this study will not cost you anything.

**10. 'How will my confidentiality be protected?'**

Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researchers named above will have access to your details. Once the interview is completed, it will be transcribed verbatim and de-identified to protect patient privacy. Your information will be stored securely in Professor Lynette Mackenzie's office at the University of Sydney. Your personal medical records will not be accessed during this study.

**11. 'What happens with the findings?'**

If you give us your permission by signing the consent document, we plan to discuss and possibly publish the findings in a peer-reviewed journal. In any publication, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, if you wish.

**12. 'What should I do if I want to discuss this study further before I decide?'**

When you have read this information, please contact Kezia Tieck to discuss a time to meet and any queries you may have. If you would like to know more at any stage, please do not hesitate to email [ktie3409@uni.sydney.edu.au](mailto:ktie3409@uni.sydney.edu.au).

**13. 'Who should I contact if I have concerns about the conduct of this study?'**

This study has been approved by the Northern Sydney Local Health District HREC. Any person with concerns or complaints about the conduct of this study should contact the Research Office who is nominated to receive complaints from research participants. You should contact them on 02 9926 4590 and quote HREC reference number LNR/17HAWKE/154.

**Thank you for taking the time to consider this study.  
If you wish to take part in it, please sign the attached consent form.  
This information sheet is for you to keep.**





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CONSENT FORM

QUALITATIVE STUDY

The Experience of Refractory Breathlessness on Everyday Life

- 1. I,..... of..... agree to participate as a subject in the study described in the Participant Information Sheet attached to this form.
2. I acknowledge that I have read the Participant Information Sheet, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the statement has been explained to me to my satisfaction.
3. Before signing this consent form, I have been given the opportunity of asking any questions relating to any possible physical and mental harm I might suffer as a result of my participation and I have received satisfactory answers.
4. I understand that I can withdraw from the study at any time without prejudice to my relationship to the investigators or HammondCare, Greenwich Hospital.
5. I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.
6. I understand that if I have any questions relating to my participation in this research, I may contact Kezia Tieck who will be happy to answer them.
7. I acknowledge receipt of a copy of this Consent Form and the Participant Information Sheet.

Complaints may be directed to the Research Office on Level 13, Kolling Building, Royal North Shore Hospital, St Leonards NSW 2065
Phone 02 9926 4590 | email NSLHD-research@health.nsw.gov.au

Signature of participant Please PRINT name Date

Signature of witness Please PRINT name Date

Signature of investigator Please PRINT name Date



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## **QUALITATIVE STUDY**

The Experience of Refractory Breathlessness on Everyday Life

### **REVOCAION OF CONSENT**

I hereby wish to **WITHDRAW** my consent to participate in the study described above and understand that such withdrawal **WILL NOT** jeopardise any treatment or my relationship with HammondCare, Greenwich Hospital or my medical attendants.

Signature

Date

Please PRINT Name

The section for Revocation of Consent should be forwarded to:

Associate Professor Lynette Mackenzie  
Discipline of Occupational Therapy  
Faculty of Health Sciences  
The University of Sydney  
75 East Street Lidcombe NSW 2141

## Interview schedule

### **Interview questions for qualitative study of the experience of breathlessness in everyday life**

Interview conducted by Kezia Tieck at Greenwich Hospital

Introduce herself explain purpose of interview and confirm consent.

I understand it may be an effort for you to speak with me today due to your breathlessness so we can go as slowly as you wish, take breaks, and stop whenever you've had enough.

#### **Can you tell me a bit about yourself and how you came to be at the clinic?**

- Age
- Social support
- Where you live, whether your house or apartment is easy for you to manage, if you have some regular help at home?
- Working?
- Previously working if unable now?
- Other medical problems affecting their health and breathlessness?

#### **How have you come to have this degree of breathlessness?**

- Underlying condition?
- And how long has breathlessness been a daily challenge for you?
- How is it today?

#### **What does your breathlessness feel like to you?**

- Breathing is rapid?

- Breath does not go all the way in /out?
- Shallow breathing?
- Breathing requires more effort?
- Chest feels tight?
- Cannot get enough air?
- Feeling out of breath?

**Generally, how would you say your breathlessness affects your life?**

- Effect on mood? Energy?
- Pain?
- Tiredness?
- Frustration?

**What does a typical day look like for you?**

- Think about ADLS that the patient mentions they can or can't do.

**What sort of activities are an issue for you in the morning afternoon and evening?**

- Showering
- Dressing
- Personal care
- Home duties
- Getting out of the house
- Driving
- Medical appointments

- Social contacts
- Community activities

**How does breathlessness affect your rest and sleep? Do you feel like you have a restful night?**

- Sleeping struggles
- Sleeping comfortably
- Sleeping position (propped up or flat)
- Can you sleep lying down?
- Open prompt – to discuss any sexual activities issue due to breathlessness if it arises.

**Is there an activity you really long to do or particularly miss doing?**

- Previous activity capability vs current capabilities.
- Can you imagine how this might be possible? Or is it not possible anymore?

**What sort of support do you have or feel you need?**

- Partner?
- Carer?
- Family?
- Friend?
- No support?
- Is this care helpful?
- How does the support help you?

**Do you have any spiritual support that you rely on for guidance or direction?**

- Faith - Influence

**How has your breathlessness affected your relationships with your partner, friends and/or family?**

- Personal relationships?
- Social relationships/activities
- Feeling like a burden
- Limiting participation for activities

**Do you feel that the people around you understand how breathlessness affects you?**

- What would help them to understand better?

**Is there some small discovery that you've made about living with breathlessness that you'd like to share, or that we could share with other people?**

- Coping technique
- Outlook
- Management strategy
- Care that's been helpful
- Support network

## Literature search strategy

Search strategy example. Search terminology applied for Medline.

1. Dyspnea/
2. (short\* adj3 breath\*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
3. breathless\*.mp.
4. (difficult\* adj2 breath\*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
5. 1 or 2 or 3 or 4
6. Chronic Disease/
7. (chronic\* or refractor\* or persistant\*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
8. severe.mp.
9. ((end or late) adj2 stage\*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
10. 6 or 7 or 8 or 9
11. 5 and 10
12. Self Report/
13. (patient\* adj2 experienc\*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
14. 12 or 13
15. 11 and 14
16. exp "Activities of Daily Living"/
17. 11 and 16
18. 15 or 17

## ICF framework in context of refractory breathlessness patients

The following domains have been set out by the World Health Organisation for the use in applying the ICF model. The table below displays the model clearly by section.

Reflecting the relevance of this model for the patient group of this study, highlighted items are areas that could potentially be relevant to someone in this population.

<p><b>Body Function</b></p> <ul style="list-style-type: none"> <li>• Mental Functions</li> <li>• <b>Sensory Functions and Pain</b></li> <li>• Voice and Speech Functions</li> <li>• <b>Functions of the Cardiovascular, Haematological, Immunological and Respiratory Systems</b></li> <li>• Functions of the Digestive, Metabolic, Endocrine Systems</li> <li>• Genitourinary and Reproductive Functions</li> <li>• <b>Neuromusculoskeletal and Movement-Related Functions</b></li> <li>• Functions of the Skin and Related Structures</li> </ul>	<p><b>Body Structure</b></p> <ul style="list-style-type: none"> <li>• Structure of the Nervous System</li> <li>• The Eye, Ear and Related Structures</li> <li>• <b>Structures Involved in Voice and Speech</b></li> <li>• <b>Structure of the Cardiovascular, Immunological and Respiratory Systems</b></li> <li>• Structures Related to the Digestive, Metabolic and Endocrine Systems</li> <li>• Structure Related to Genitourinary and Reproductive Systems</li> <li>• <b>Structure Related to Movement</b></li> <li>• Skin and Related Structures</li> </ul>
<p><b>Activities and Participation</b></p>	<p><b>Environmental Factors</b></p>



<ul style="list-style-type: none"> <li>• Learning and Applying Knowledge</li> <li>• General Tasks and Demands</li> <li>• Communication</li> <li>• Mobility</li> <li>• Self Care</li> <li>• Domestic Life</li> <li>• Interpersonal Interactions and Relationships</li> <li>• Major Life Areas</li> <li>• Community, Social and Civic Life</li> </ul>	<ul style="list-style-type: none"> <li>• Products and Technology</li> <li>• Natural Environment and Human-Made Changes to Environment</li> <li>• Support and Relationships</li> <li>• Attitudes</li> <li>• Services, Systems and Policies</li> </ul>
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It is clear all areas potentially could have factors influencing the patient group, particularly activities and participation which is disrupted in a significant way by the underlying health condition.

An example of how the disabilities associated with refractory breathlessness may be linked with the three levels of functioning specified in this model, and tied back to the health condition below. This is an example only but could be utilised for each patient interviewed.

<b>Health Condition</b>	<b>Impairment</b>	<b>Activity Limitation</b>	<b>Participation Restriction</b>
Refractory Breathlessness	Impaired respiratory function	Difficulty engaging in social situations as it is too tiring	Limited social participation leads to isolation and few

		going out to meet friends or family.	social relationships.
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The next chart shows how the different levels of disability are linked to the levels of intervention and prevention.

	<b>Intervention</b>	<b>Prevention</b>
<b>Health Condition</b>	<ul style="list-style-type: none"> <li>• Medical treatment</li> <li>• Medications</li> <li>• Breathing aids such as oxygen</li> <li>• Breathlessness Clinic</li> </ul>	<ul style="list-style-type: none"> <li>• Nutrition</li> <li>• Immunisations to prevent flu seasonally.</li> <li>• Staying as physically well as possible.</li> </ul>
<b>Impairment</b>	<ul style="list-style-type: none"> <li>• Medical treatment</li> <li>• Medications</li> <li>• Breathing aids such as oxygen</li> <li>• Breathlessness Clinic</li> </ul>	<ul style="list-style-type: none"> <li>• Not preventable but can be managed effectively as possible.</li> </ul>
<b>Activity Limitation</b>	<ul style="list-style-type: none"> <li>• Assistive devices</li> <li>• Family support</li> <li>• Breathlessness Clinic support</li> </ul>	<ul style="list-style-type: none"> <li>• Rehabilitation to try and slow progression of refractory breathlessness.</li> <li>• Try and prevent isolation but some sort of activity engagement in a meaningful setting.</li> </ul>
<b>Participation Restriction</b>	<ul style="list-style-type: none"> <li>• Assistive devices such as motorised scooters to mobilise.</li> <li>• Universal accessible design</li> </ul>	<ul style="list-style-type: none"> <li>• Environmental changes</li> <li>• Universal design</li> </ul>

Australian Occupational Therapy Journal Author Guidelines  
Australian Occupational Therapy Journal Requirements

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**1. SUBMITTING TO AUSTRALIAN OCCUPATIONAL THERAPY JOURNAL**

Thank you for your interest in Australian Occupational Therapy Journal. Submissions are only received through the “Scholar One” manuscript central website accessed through the journal home page.

Authors should register at <https://mc.manuscriptcentral.com/aotj> and follow online submission instructions. Manuscripts that fail to meet requirements of the Author Guidelines will be rejected without review.

For help with submissions, please contact the Editorial Assistant: [aot.eo@wiley.com](mailto:aot.eo@wiley.com)

**Australian Occupational Therapy Journal Article Submission “Checklist for Authors”**

The following checklist will appear as part of the online submission process. Authors must confirm adherence to all items.

I have adhered to all of the following in the manuscript submitted

- The manuscript was double-spaced in 12 point Times New Roman or Times Roman font and does not exceed the permitted word count.
- I used Australian-English spelling.
- The abbreviation of “OT” or “OTs” was not used.
- The submitted manuscript did not contain any identifying information about specific people, programs, locations or study sites.
- I consulted the *Publication Manual of the American Psychological Association, Sixth Edition* and/or the official companion APA Style Blog (<http://blog.apastyle.org/apastyle/>) to prepare correct citations and references. All journal articles published after 1997 included the digital object identifier (doi) presented according to APA style rules.
- The corresponding author obtained and included his/her ORCID number.

- The “Abstract” was no longer than 300 words and used the following headings: Introduction; Methods; Results; Conclusion.
- Abbreviations followed the *Publication Manual of the American Psychological Association, Sixth Edition* /or the official companion APA Style Blog (<http://blog.apastyle.org/apastyle/>); this included abbreviations in the reference list.
- Up to five keywords were selected from either the U.S National Library of Medicine Medical Subject Headings (MeSH) (<https://www.nlm.nih.gov/mesh/>) or the Cumulative Index to Nursing and Allied Health Literature Thesaurus. Only MeSH or CINAHL words were used.
- The Main Document used subheadings set out in the Guidelines.
- If my study used humans, I provided details of the Institutional Review Board, Human Research Ethics Committee or equivalent delegated authority in the Scholar One form where indicated and these details were also written into the Method Section of the manuscript (blinded for review)
- Research articles followed the reporting guidelines presented in <http://www.equator-network.org/>. I note reviewers will be asked to evaluate the manuscript in light of these guidelines. I provided evidence of adherence as a supplementary document: e.g., prospective clinical trial registration.
- A section called “Key Points for Occupational Therapy” was included at the end of the paper, before “references”.
- A section called “Declaration of Authorship” was included after “Key Points” and before “references”. The declaration stated the contribution of each author to the paper and any conflict of interest. I/we used wording that demonstrated adherence to the roles and responsibilities of authors described in the International Committee of Medical Journal Editors (ICMJE) recommendations (<http://www.icmje.org/>).
- A section called “Funding” was included after the author declaration.
- People or institutions who were acknowledged gave written permission.

## **2. EDITORIAL CONSIDERATIONS**

### **Aims and Scope**

The *Australian Occupational Therapy Journal* is a leading international peer reviewed publication presenting influential, high quality innovative scholarship and research relevant to occupational therapy.

The journal is the official research publication of the professional peak body, Occupational Therapy Australia. The journal publishes empirical studies, theoretical papers, reviews and invited scholarly commentary.

The aim of the journal is to be a leader in the dissemination of scholarship and evidence to substantiate, influence and shape policy and occupational therapy practice locally and globally.

Preference will be given to papers that have a sound theoretical basis, methodological rigour with sufficient scope and scale to make important new contributions to the occupational therapy body of knowledge.

Topics may include:

- how participation in occupation is affected by body structures and function domains
- participation in occupations across the lifespan
- environments affecting engagement in occupation and occupational therapy services (physical, social, policy etc.)
- interaction of person, environment and occupation factors to influence health
- people who receive, could receive or who are impacted by occupational therapy practice, policy or education;
- assessments measuring constructs relevant to and applied in occupational therapy research, practice or education;
- occupational therapy interventions (development, implementation and impact)
- scope of occupational therapy practice
- professionalisation and professionalism in occupational therapy
- pedagogy and educational practice involving occupational therapy, including interprofessional, multidisciplinary, transdisciplinary and single discipline research that includes occupational therapy and/or occupational therapy students/ staff.

Authors must position their study in an appropriate and sound theoretical and empirical context; with a critical analysis of relevant literature in the Introduction section. The manuscript must demonstrate how findings make an important contribution to knowledge in the field.

For quantitative papers, authors are encouraged to demonstrate how their studies enable replication, generalizability and contribute to understanding possible or actual causality. Typically this will involve reporting using guidelines such as those available in the EQUATOR network. Authors must use measures that are well validated and have proven psychometric properties.

Authors are encouraged to triangulate data to substantiate their findings where appropriate, for example: self-report measures and performance observation measures; therapist and consumer measures/ perspectives.

The journal preferences qualitative research that contributes to development of substantive or formal theory, is empirically grounded, is internally reflexive and has explored its value for different groups including study participants. Studies that demonstrably illuminate aspects of occupational therapy and can thus inform decision making will be of particular interest to readers. Qualitative studies must demonstrate transferability, dependability, trustworthiness, and credibility.

In mixed method research, authors are required to clearly outline how the a-priori design demonstrates integration of qualitative and quantitative methods during data collection, analysis and reporting. When a mixed method approach is reported, authors should clearly identify the design (e.g., sequential explanatory, sequential exploratory, concurrent nested, etc.) and report which data took priority during data collection and analysis (e.g., did qualitative data lead the results with support from the quantitative?). Consideration should be given to whether the approach used is mixed or multiple methods.

Instrumentation studies present the development and/or evaluation of the psychometric properties of a tool – reliability, validity, sensitivity, clinical utility. The journal has a preference for standardised taxonomies such as COSMIN.

The *Australian Occupational Therapy Journal* receives many more papers than it can publish. Studies may be methodologically appropriate, have significant or original results, but that may not mean the paper is a significant contribution to new knowledge. The journal aims to publish research that will provide a rigorous, relevant evidence base to inform professional practice and decisions relating to occupational therapy. Authors must demonstrate that their research is thus not only technically competent but is an original and significant contribution to knowledge and practice.

The journal will consider multidisciplinary or interprofessional studies that include occupational therapy, occupational therapists or occupational therapy students, so long as 'key points' highlight the specific implications for occupational therapy, occupational therapists and/or occupational therapy students and/or consumers.

If authors extract material from single larger interprofessional or multidisciplinary studies for an occupational therapy-specific study, these papers are only acceptable if distinct and separate questions are asked, if a theoretically and empirically grounded rationale is provided for the extracted study, and if the methodology is appropriate to the question

If authors are submitting a paper where data is derived from a larger study, authors are required to disclose all related publications that are published, submitted or under review. If authors state that aspects of the study have already been published, a case must be made to demonstrate how the present paper is distinctive and makes a significant contribution to knowledge.

### **Conditions of submission**

Papers submitted to the journal must not be presenting content that has been previously published. The only exceptions to this rule are the following: conference abstracts; part of a published lecture or academic thesis; as an electronic preprint; poster/ abstract/ oral presentation presented at a conference or scientific meeting where proceedings are available on a pre-print server.

Papers that present clinical trials are not deemed to have been previously published if they appear in clinical trials registers and/or if results in such registers are presented as a brief summary or table.

Papers submitted to the journal must not be under consideration for publication elsewhere.

If accepted for publication, authors agree the paper will not be published elsewhere in the same form, in English or in any other language, including electronically without the written consent of the copyright-holder which is the journal publisher. Authors must be aware that in signing the copyright form they are entering a legal agreement not to disseminate or republish the journal-article on any file sharing site, by email attachment, in thesis dissertations or in any other form. Authors are able to disseminate the pre-production manuscript if they own the copyright and they are able to include citation details of the Australian Occupational Therapy Journal published paper on such documents.

All papers submitted to the *Australian Occupational Therapy Journal* are subject to automated text-matching software screening which reports a % similarity index.

### **Editorial Processes**

All submissions are inspected by the Editorial Team first to determine whether all criteria in the “Checklist for Authors” have been met. A paper that does not meet criteria will be rejected and returned to authors.

Second, Editorial inspection determines whether or not papers are within the journal “Aims and Scope”. The Editorial Board may decide to reject any paper not deemed to be within the Aims and Scope of the journal. A reason for rejection will be provided. The decision is final.

A paper deemed to be in line with the “Aims and Scope” of the Journal will be blind-reviewed by one member of the Editorial or Review Board and either a specialist guest-reviewer or another member of the Editorial or Review Board. Reviewers will provide feedback using the *Australian Occupational Therapy Journal* review-form. Reviewers will be directed to consider the methodological quality of the study and may choose to use standardised critical appraisal tools. Reviewers will provide blind comment to authors regarding the manuscript. Reviewers will make confidential recommendations to the Editorial Board regarding publication priority. The Editorial Board will use reviewer reports to inform decisions regarding acceptance, rejection, or provision of opportunities to revise and resubmit. Resubmissions have no guarantee they will be accepted. A rejection decision is final; no further correspondence will be entered into.

An accepted paper is submitted to the WILEY production process.

Authors will receive the page-proofs for their paper and are required to review for accuracy; any changes beyond accuracy may incur a charge. The author-approved proof is sent to the Editor in Chief for final review. The Editor and the Publisher reserve the right to make minor modifications to typescripts to correct spelling or grammar issues that have been overlooked, or eliminate ambiguity and repetition. A paper is not approved for publication, regardless of the stage of review or correspondence sent and received until the Editor in Chief approves publication of the final proof. If an author identifies an error after publication that is their responsibility, he/she/they are responsible for costs associated with correction and publication of corrigium.

### **3. ETHICAL CONSIDERATIONS**

This journal is a member of the Committee on Publication Ethics (COPE).

#### ***Human Studies***

For manuscripts reporting studies involving human participants or data originally generated from human participants (e.g., chart reviews, program evaluations, secondary data analyses), we require a statement identifying how ethical and /or research governance approval was obtained, where and under what authority it was granted. Authors must provide the name of the committee and state the reference number where appropriate. The name of the approving committee/s should be included in the manuscript (but de-identified for blind review purposes) – it is not acceptable to refer to “researcher institutional ethics committees” in general.

For research conducted in Australia or through Australian institutions the National Statement on Ethical Conduct in Human Research 2007 - updated May 2015 applies (<https://www.nhmrc.gov.au/guidelines-publications/e72>).; for research with Indigenous Australians this also includes the companion document “Values and Ethics - Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research” (NHMRC, 2003).

For research conducted by investigators in countries other than Australia, there is a requirement for authors to demonstrate that the research complied with principles of the World Medical Association Declaration of Helsinki Ethical Principles for Medical Research involving Human Subjects as amended October 2000 and that research was conducted with institutional or equivalent approvals consistent with the World Health Organization “Standards and operational guidance for ethics review of health-related research with human participants” (2011). Failure to provide this information or demonstrate this requirement will result in the submission being rejected.

### ***Clinical Trial Registration***

Clinical trials will normally be prospectively registered in a publicly accessible database and clinical trial registration numbers should be included in all papers that report results. Include the name of the trial register and your clinical trial registration number at the end of your abstract.

If your trial is not registered, or was registered retrospectively, please explain the reasons for this in the cover letter.

### ***Research Reporting Guidelines***

Accurate and complete reporting enables readers to fully appraise research, replicate it, and use it. The *Australian Occupational Therapy Journal* will publish positive, negative and inconclusive results as long as the research is rigorous.

Authors must adhere to research reporting standards presented in the EQUATOR network (<http://www.equator-network.org/>).

Authors must submit the relevant EQUATOR reporting guideline checklist as a not-to-be-published supplementary document to the submission. If authors do not believe one of these guidelines is appropriate a rationale must be provided in the cover letter and an alternative standards benchmark provided.

### ***Roles and Responsibilities of Authors***

An author is someone who demonstrates roles and responsibilities defined by the International Committee of Medical Journal Editors (ICMJE) (<http://www.icmje.org/>). A declaration must be made to this effect.



The ICMJE recommends that authorship be based on the following criteria: (i) Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; (ii) Drafting the work or revising it critically for important intellectual content; (iii) Final approval of the version to be published; and (iv) Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

### ***Conflict of Interest***

Authors should disclose any actual or perceived conflicts of interest. Any interest or relationship, financial or otherwise that might be perceived as influencing an author's objectivity is considered a potential source of conflict of interest. These must be disclosed when directly relevant or directly related to the work that the authors describe in their manuscript. Potential sources of conflict of interest include, but are not limited to, patent or stock ownership, membership of a company board of directors, membership of an advisory board or committee for a company, and consultancy for or receipt of speaker's fees from a company. The existence of a conflict of interest does not preclude publication. If the authors have no conflict of interest to declare, they must also state this at submission. It is the responsibility of the corresponding author to review this policy with all authors and collectively to disclose with the submission ALL pertinent commercial and other relationships.

### ***Funding***

Authors must make a funding statement. This will appear at the end of the paper before the reference section. Authors should list all funding sources. All funding received for work described within a submitted manuscript must be acknowledged in the funding disclosure section. Provide the name of the funder, the grant number, and the name of the principal investigator as applicable. If there was no specific study funding, then the authors should report the following statement: "This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors."

### ***Acknowledgements***

The contribution of colleagues or institutions can be acknowledged. Personal thanks and thanks to anonymous reviewers are not appropriate. Acknowledgements should contain information on individuals who have contributed to this work but did not meet the criteria for authorship or decline to be included as an author. All those individuals who are named in the acknowledgements must be contacted by the author and agree to have their name included. Each individual's specific contribution to the work must be briefly stated. Acknowledgements of general support or mentorship will be deleted by the editor as acknowledgements are only for those individuals who have provided a specific contribution to this work. In addition, the authors must provide information on previous dissemination of this work, in part or whole, at conferences or workshops. Prior presentation of the paper at a meeting should be briefly described last.

## **4. ARTICLE TYPES AND REQUIREMENTS**

<b>Type of Article</b>	<b>Word limit (excluding abstract, references, tables and</b>	<b>Abstract required - word limit</b>	<b>Number of references allowable</b>	<b>No. of tables or figure files</b>
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Feature	figures			
	5000	300	35	4
Review *	5000	300	35	4#
Viewpoints (invited only)	2000	150	15	2
Critically Appraised Papers	800	NA	10	0
Letter to Editor	300	NA	3	0

\* Refer to full detail regarding length, references and tables for Review Articles below

# Usually published in online-only format

### All articles

All articles must be accompanied by a cover letter that addresses how the paper complies with conditions of submission.

If content is derived from a larger study, study series or previously published work, the authors must explain in the cover letter how their submission makes an original and substantial contribution to new knowledge and they must include citations and doi links for all related/ derivative studies.

The cover letter should include a statement regarding written permissions for photographs, personal communications, and copyrighted material. These written permissions should be attached to the cover letter.

The cover letter should confirm that any person or institution named in the acknowledgements has given permission

### Feature Articles

Feature Articles can be in the form of research papers, theoretical papers, case reports or descriptive articles. Manuscripts should not exceed 5000 words including Key Points, Author Declaration and conflict of interest, funding and acknowledgement. The Title, Abstract and References are not included in the word count.

Feature articles should contain the following:

*Title page:* This will be a separate file to the main document – upload using the “title page” option in Scholar One. The title page should contain:

(i) a short informative title that contains the major content concepts. The title should not contain abbreviations (see our best practice SEO tips);

(ii) the full names, qualifications and designations of the authors;

(iii) the full addresses of the authors’ affiliations;

- (iv) a short running title (no more than 40 characters, abbreviations are permitted);
- (v) authors' declaration of authorship contribution\*;
- (vi) funding statement\*;
- (vii) conflict of interest statement\*;
- (viii) acknowledgements\*;
- (ix) word length for the main text excluding references, abstract and tables;
- (x) word length of the abstract;
- (xi) the number of references, figures and tables include as part of article;
- (xii) Designate the corresponding author by providing his or her full address, telephone and fax numbers, and e-mail address.
- (xiii) A minimum of five MeSH or CINAHL terms should be included as key words

\*In the printed publication these will appear at the end of the paper before "references" – they are included here in the title page because this is not sent out to reviewers.

*Structured abstract:* 300 word limit including Introduction, methods, results and conclusion.

*Introduction:* The aims of the article should be clearly stated and a theoretical framework (if applicable) should be presented with reference to established theoretical model(s) and background literature. A succinct review of current literature should set the work in context. The introduction should not contain findings or conclusions. The aim of the research should be stated at the end of the introduction section.

*Methods:* This should provide a description of the method (including recruitment of subjects, study procedures, instruments and data analysis) in sufficient detail to allow the work to be repeated by others. Name (but de-identify for review) the Human research Ethics Committee/s or equivalent if human participants were involved.

*Results:* Results should be presented in a logical sequence in the text, tables and figures. Participant characteristics are presented in results. The same data should not be presented repetitively in different forms.

*Discussion:* The discussion should consider the results in relation to the study purpose, practice and scholarly context. The relationship of your results to the work of others and relevant methodological points could also be discussed. Limitations of the study should be identified. Implications for practice and future research should be considered. A conclusion section may be used but is not mandatory.

*Key Points for Occupational Therapy:* This is included at the end of the paper, before "references". It comprises a bulleted list of three points summarising implications of the paper for occupational therapy practice/ policy or and or education. These should not exceed 45 words in total (that is, 10-15 words each). Each point should reflect the journal's aim and scope above and must not simply restate the findings.

*References:* No more than 35 references.

*Standard inclusions of Author Declaration including conflict of interest, funding statement, acknowledgement if appropriate:* This will be a separate file to the Main Document – upload as “supplementary file” not for review. Normally no more than 100 words.

*Tables and/or Figures:* No more than 4 will be included. Large Tables or Figures may be published as on-line only files to permit efficient production of the print-version of the journal. The file link will be published in the print version.

Appendices are not permitted.

(Reporting Guidelines will normally be included as a non-published supplementary file in the submission. In some cases, e.g., CONSORT flow-chart, aspects of the guidelines may be included in the main document)

## **Reviews**

Narrative reviews, scoping reviews, meta-syntheses, systematic reviews and meta-analyses are included in this category.

Review articles should contain the following:

*Title page:* This will be a separate file to the main document – upload using the “title page” option in Scholar One. The title page should contain:

(i) a short informative title that contains the major content concepts. The title should not contain abbreviations (see our best practice SEO tips);

(ii) the full names, qualifications and designations of the authors;

(iii) the full addresses of the authors’ affiliations;

(iv) a short running title (no more than 40 characters, abbreviations are permitted);

(v) authors’ declaration of authorship contribution\*;

(vi) funding statement\*;

(vii) conflict of interest statement\*;

(viii) acknowledgements\*;

(ix) word length for the main text excluding references, abstract and tables;

(x) word length of the abstract;

(xi) the number of references, figures and tables include as part of article;

(xii) Designate the corresponding author by providing his or her full address, telephone and fax numbers, and e-mail address.

(xiii) A minimum of five MeSH or CINAHL terms should be included as key words; Note that MeSH key words are reviewed by an indexer and may be edited.

\*In the printed publication these will appear at the end of the paper before “references” – they are included here in the title page because this is not sent out to reviewers.

*Structured abstract:* No more than 300 words including Introduction, methods, results and conclusion.

*Introduction:* A rationale and context for the review must be provided. The aim of the review should be stated at the end of the introduction section.

*Methods:* The methodology used to design and conduct the review should be presented in sufficient detail to allow the work to be repeated by others.

*Results:* Results should be presented in a logical sequence in the text, tables and figures. Details of sources retrieved and analysis findings are presented in results. The same data should not be presented repetitively in different forms.

*Discussion:* The discussion should consider the results in relation to the study purpose, practice and scholarly context. The relationship of your results to the work of others and relevant methodological points could also be discussed. . Limitations of the review should be identified. Implications for practice and future research should be considered. A conclusion section may be used but is not mandatory.

*Key Points for Occupational Therapy:* This is included at the end of the paper, before “references”. It comprises a bulleted list of three points summarising implications of the paper for occupational therapy practice/ policy or and or education. These should not exceed 45 words in total (that is, 10-15 words each). Each point should reflect the journal's aim and scope above and must not simply restate the findings.

*References:* Review articles use references as part of the introduction, method and in the discussion to frame the study. They also present references as ‘data’ or findings. Authors should consider these two reference types when preparing the manuscript. Up to 20 “usual” main document references may be used (i.e., sources cited in the introduction, method and discussion to place the review findings in context). There is no limit on the number of ‘references’ reported in the research results. Typically author, title, source details will be presented in ‘results tables’, but the full citation with doi will appear in the reference list along with “usual” references.

*Standard inclusions of Author Declaration including conflict of interest, funding statement, acknowledgement if appropriate:* This will be a separate file to the Main Document – upload as “supplementary file” not for review. Normally this will be no more than 100 words.

*Tables and/or Figures:* No more than 4 will be included. Large Tables or Figures may be published as on-line only files to permit efficient production of the print-version of the journal. The file link will be published in the print version.

Appendices are not permitted.

(Reporting Guidelines will normally be included as a non-published supplementary file in the submission)

## **Viewpoints**

Viewpoints are Invitation only papers. Viewpoints provide a forum for the debate and discussion of pertinent occupational therapy issues and related concerns. Authors are encouraged to discuss topical and controversial issues, and to do so in a manner that sheds light on or challenges established practices and beliefs. In many cases, discussion will require attention to varying opinions. A viewpoint may be an appropriate avenue for readers

to debate the content of previous Viewpoints or other articles that have appeared in the journal. Proposals for Viewpoint articles can be made to the Editorial Board via the Editorial Office ([aot.eo@wiley.com](mailto:aot.eo@wiley.com)); provide a rationale, brief outline of the topic and the position to be taken.

Viewpoints should contain the following:

*Title Page:*

*Abstract:* No more than 150 words

*Main document:* No more than 2000 words,

*References:* No more than 15 references.

*Author declaration including conflict of interest:* This should be supplied, to be published at the discretion of the Editorial Board

### **Critically Appraised Papers**

Critically Appraised Papers are solicited by the Editorial Office. If you would like to propose an idea for a CAP, please contact the Editorial Office ([aot.eo@wiley.com](mailto:aot.eo@wiley.com)) with a brief outline of the topic.

### **Letters to the Editor**

Letters to the Editor will only be published online.

*Main Document:* No more than 300 words

*References:* No more than 3 references using APA format including doi numbers.

*Author declaration including conflict of interest:* This should be supplied, to be published at the discretion of the Editorial Board

## **5. PREPARING THE MANUSCRIPT**

### **Writing for Search Engine Optimization**

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