DOI: http://doi.org/10.4038/jccp.v53i2.7967

Experience in managing refractory breathlessness in non-cancer patients undergoing palliative care

Ramadasa GU[1,2], Karunatillake R[2], Hathlahawatta C[2], Jamaldeen Z[2], Thaibudeen MA[2], Ediriweera de Silva RE[3], Jayasinghe S[4]

Journal of the Ceylon College of Physicians, 2022, **53**, 94-100

Abstract

Patients with end stage organ failure suffer from a range of clinical symptoms including breathlessness. The latter is a multidimensional symptom, consisting of affective as well as physical aspects. We intend to describe the management of breathlessness outside of the context of the primary disease and describe the inputs of a Palliative Care Team in the management.

The clinical cases highlight how the three cycles of breathlessness; breathing, thinking and functioning (BTF) were addressed through a multidisciplinary team. The case series shows the utility of a simple framework (i.e. three cycles), use of morphine and the importance of rehabilitation to improve breathlessness of these patients. Assessment of the three domains of breathlessness and identification of the strongest driver and targeting the treatment strategy for individual patients through a multidisciplinary approach is effective in providing relief and improving quality of life within a short period of time.

Key words: palliative, non-cancer, breathlessness

Introduction

Patients with end-stage organ failure suffer from a range of clinical symptoms and breathlessness is one of them. Breathlessness, a multidimensional symptom, consists of affective as well as physical aspects derived from multiple physiological, psychological, and environmental factors.[1] It is often associated with fatigue, cough, muscle weakness, poor sleep, pain, anxiety and depression and significantly decreases the quality of life of patients.[2]

Breathlessness is prevalent in chronic respiratory diseases as well as chronic cardiac diseases. In patients with chronic obstructive pulmonary disease (COPD), breathlessness is reported in over 80% of patients in the community, and moderate-to-severe breathlessness was reported by 40% of patients with COPD in primary care.[3,4] It is also reported that in the Asia Pacific region, heart failure is a common diagnosis in patients presenting to the emergency department with a principal symptom of breathlessness and majority (86%) of them been admitted to the hospital.[5]

Refractory breathlessness is a distressing symptom, and the global prevalence is rising with ageing populations and increasing multi-morbidity.[6]

Management of breathlessness is hampered by its inherent complexity. In Sri Lanka, management of refractory breathlessness through palliative care is still an unmet need in many patients with non-cancer diseases such as advanced cardiac and respiratory failure.[7]

The objective of this study was to describe the methods used to assess and manage breathlessness, identify contributory factors that aggravate breathlessness and to describe the establishment of a Palliative Care approach using the Breathing, Thinking, Functioning (BTF) model in a resource poor setting. This pragmatic clinical approach can be used in any advanced cardiorespiratory disease.

[1]*Department of Medicine, Faculty of Medicine, Sabaragamuwa University, Sri Lanka,* [2]*Provincial General Hospital, Ratnapura, Sri Lanka,* [3]*Department of Family Medicine, Faculty of Medicine, University of Colombo, Sri Lanka,* [4]*University of Colombo, Sri Lanka*

Correspondence: RGU, e-mail: uramadasa@med.sab.ac.lk, uramadasa@yahoo.co.uk

https://orcid.org/0000-0001-9028-3638

Received 21 February 2022, accepted 18 June 2022.

Breathing, Thinking, Functioning (BTF) model

When evaluating chronic breathlessness, a simple and easily understandable BTF Clinical model which was developed by Cambridge Breathlessness Intervention Service (breathing, thinking and functioning cycle) was used.[3] It is a tool which explains why people feel breathless and provide information to develop personalized breathlessness management plan to each individual patient (Figure 1).

Breathing cycle

Inefficient work of breathing leads to increased respiratory rate, use of accessory muscles, and dynamic hyperinflation.

Thinking cycle

Thoughts about dying, misconceptions, attention to the sensation of breathlessness, memories, past experiences lead to anxiety, distress and feeling of panic.

Functioning cycle

Deconditioning of limbs, chest wall and accessory muscles due to inactivity further aggravates the inactivity booming a vicious cycle. This causes a tendency to self-isolate and increases the dependency on care givers.

Managing patients with refractory breathlessness

The team was established in Rathnapura Provincial General Hospital, by forming a network of healthcare personnel who were guided by the first author, consisted of specialists, nursing staff, medical officers, occupational therapists, physiotherapists, and social workers who volunteered to provide palliative care. The underlying diagnoses of patients were chronic hypersensitive pneumonitis related end stage interstitial lung disease (n=2), end stage chronic obstructive pulmonary disease (n=1), right heart failure secondary to inoperable atrial septal defect (n=1), and end stage cardiac failure secondary to ischemic heart disease (n=2).

Each patient was regularly assessed in the Palliative Care Clinic by the Consultant Physician, the Consultant Respiratory Physician, Consultant Cardiologist and other members of the multidisciplinary team. They were independently followed up at the Respiratory and Cardiology clinics for the optimal management of the primary condition.

Non-cancer-related dyspnoea

Case 1

A 48-year-old patient with end-stage chronic hypersensitive pneumonitis, was breathless at rest with a dyspnea scale of mMRC Grade 4. He was on home oxygen and showed overt signs of anxiety and had frequent episodes of panic attacks. He was physically and psychologically dependent on oxygen and wheel chair bound due to upper and lower limbs muscle weakness, disuse atrophy, stiffness and steroid induced myopathy. He had dyspepsia, loss of appetite and low mood. He was dependent on his 11-year-old son for mobility. All three components of the breathlessness cycle were affected and his functioning cycle was disproportionately affected, markedly reducing the quality of life. Limited pulmonary rehabilitation was initiated with upper and lower limb muscle strengthening exercises. Occupational therapist constructed an oxygen stand with wheels to assist in mobility while using oxygen.

For the breathing cycle he was given optimal management with bronchodilators, trained on breathing exercises to strengthen inspiratory muscles and was given a hand-held fan. For the thinking cycle he was

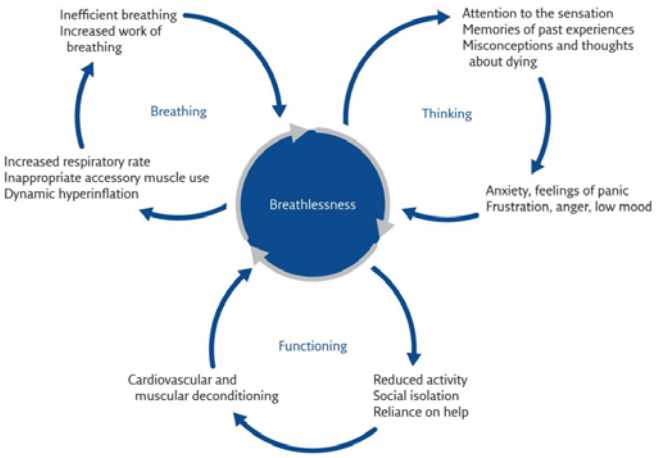

Figure 1. Breathing, Thinking, Functioning (BTF) model for assessment of breathlessness.

trained on relaxation techniques and coping with panic attacks. He was provided psychological support by a Consultant Psychiatrist and a counselor. The social worker assisted with financial support through Samurdhi project. He was commenced on alprazolam 0.25 mg nocte. Immediate-release (IR) morphine 2.5 mg 6 hourly and fluoxetine 20 mg mane and inhalers were continued. Home visits were made.

Quality of life of the patient improved with improving breathlessness. He was mobilized wheeling the oxygen cylinder on the stand and taken off oxygen at rest. His mood improved and the panic attacks became infrequent. After 4 months he passed away due a cardiovascular event. The child developed separation anxiety which was managed by the psychiatrists.

Case 2

A 43-year-old man with end-stage interstitial lung disease had intractable shortness of breath even at rest. He felt fatigued, lethargy and was oxygen dependent. He had low mood, anxiety and developed repeated panic attacks which adversely affected the well-being of his three children. His twin sons were preparing for their GCE O/L exam and this made him suffer from guilt as he felt his illness was a disruption to their studies. They were unprepared and felt hopeless and unsupported. He was bed bound mostly and dependent on activities of daily living. His all three domains of BTF cycle were affected but most disabling was the thinking cycle. He was trained on relaxation techniques, counselled how to cope with panic attacks, and commenced on anxiolytics. He refused limited rehabilitation programme. He was started on Immediate Release (IR) morphine 2.5 mg 6 hourly. Counseling and psychological support was given to the family. He had a peaceful death two weeks later at home and his death strangely coincided with the last day the children had successfully completed their O/L examination.

Case 3

A 65-year-old man diagnosed with COPD presented with shortness of breath when attending to activities of daily living and had severe debility due to illness (Dyspnea scale mMRC 4, GOLD 3 group D disease). He had two hospital admissions during the last 6 months. He was on optimal medical treatment with pulmonary rehabilitation program for a year. He was anxious and frequently suffered from depressive symptoms. BTF cycle was affected in him to a variable extent, but mostly ineffective breathing technique and poor energy conservation. We discussed about mobility aids and energy conservation methods and taught him controlled breathing techniques and pursed lip breathing. A hand-held fan and relaxation methods were taught to use specially during panic attacks. Reassurance and counselling were done and anxiolytics were recommended if needed. For the functioning cycle he was referred again for the pulmonary rehabilitation program. After optimizing other pharmacological measures, low dose morphine was commenced. Psychological support was given to the patient and family.

Patient's mood, coping abilities, number of hospital admissions were improved and he started enjoying leisure activities.

Case 4

A 54-year-old woman was admitted with exacerbation of severe heart failure due to a large inoperable atrial septal defect with left to right shunt. She had shortness of breath even with mild exertion needing assistance for self-care (NYHA stage IV). She was fatigued, weak, depressed and dependent on oxygen with recurrent hospital admissions. Family was anxious and had unrealistic expectations. The prognosis and disease progression were explained and she was reassured. Oral (liquid) morphine 2 mg 8 hourly was commenced and cardiac medications optimized. Her breathlessness improved and she was able to mobilize requiring a minimal dose of oxygen.

She was not deemed fit to undergo cardiac rehabilitation. She was readmitted a month later and the morphine dose was increased. She was comfortable and mobilizing around the house and was able to attend to self-care. Her mood and quality of life improved and the number of hospital admissions were reduced. However, her cardiac functions continued to deteriorate and she died a few months later.

Case 5

A 65-year-old man with end stage cardiac failure after coronary artery bypass graft (CABG), presented to Coronary Care Unit, with exacerbation of shortness of breath. He was breathless at rest, dependent on oxygen and was unable to attend to self-care without support (NYHA stage IV). He was bed bound and distressed due to the intractable shortness of breath but understood the prognosis. He was depressed due to the unexpected outcome after the surgery. To improve the breathing cycle, he was commenced oral IR morphine 2.5mg hourly which was titrated to 2.5 mg 4 hourly and converted to oral Morphine SR 10mg 12 hourly. He was seen by consultant psychiatrists, counseled and commenced on anti-depressants. At the time of discharge, he was mobilizing without oxygen and was able to attend to his self-care. He did not have hospital admissions due to exacerbation of symptoms over the next 6 months. He was seen in the Palliative care clinic for a few visits every 2 to 4 weeks and continued the follow up in the Cardiology clinic.

Case 6

A 54-year-old patient with end stage cardiac failure secondary to ischemic heart disease was admitted to Coronary Care Unit (CCU) due to an exacerbation. He was oxygen dependent and dyspneic even at rest (NYHA stage IV) and had repeated hospital admissions with exacerbations. He was counseled and advised regarding his worries. He was commenced on oral morphine 2.5 mg 8 hourly to improve the breathing cycle and felt much better with the initial few doses. He was able to be mobilized independently and discharged home. He did not have significant financial or care giver problems. Patient was well aware and prepared for the expected outcome of the disease. He visited palliative care clinic 2 to 4 weekly and did not have exacerbations over the next 6 months.

Discussion

Our case series demonstrates the potential for an informal palliative care team in a limited resource setting to manage distressing breathlessness using simple measures, appropriate interventions and drugs to relieve breathlessness.

Table 1. Summary of the application of BTF to individual patients

Case number	*Breathing cycle*	*Thinking cycle*	*Functioning cycle*
Case 1	Rapid and shallow breathing	Panic attacks Psychological dependency on oxygen Low mood	Upper limb and lower limb muscle weakness. Wheelchair bound with muscle contractures
Case 2	Rapid and shallow breathing specially during panic attacks	Low mood, anxiety, frequent panic attacks	Fatigue, lethargy, bed bound, dependent on activities of daily living
Case 3	Rapid and shallow breathing with shortened expiratory phase leading to ineffective breathing technique	Anxious, depressive episodes, could not enjoy leisure activities.	Debilitated with increased dependency on the caregiver for activities of daily living. Muscle deconditioning and poor energy conservation
Case 4	Rapid and shallow breathing	Low mood	Requiring assistance for self-care, fatigue, weakness
Case 5	Rapid and shallow breathing	Distressed, low mood	Requiring assistance for self-care, bed bound
Case 6	Rapid and shallow breathing	Psychologically balanced and prepared for the expected outcome	Requiring assistance for self-care

We elicited patient's experience of breathlessness, how it affected their lifestyles, activities of daily living, symptom burden and the impact on quality of life of the patient as well as family members and targeted therapeutic interventions accordingly with much success (see Table 2).

Table 2. Summary of interventions and outcomes on individual patients

Case number	*Multidisciplinary non-pharmacological interventions*	*Pharmacological interventions*	*Outcome*
Case 1	Limited pulmonary rehabilitation: oxygen stand with wheels to mobilize, breathing exercises, relaxation techniques, hand held fan. Psychological support and counselling to cope with panic attacks. Psychological and social support to patient and family.	Alprazolam 0.25 mg nocte Oral morphine IR 2.5 mg 6 hourly Fluoxetine 20 mg mane Optimized the respiratory medications.	Improved breathlessness, was able to mobilize wheeling the oxygen cylinder off oxygen at rest, mood elevated, very occasional panic attacks.
Case 2	Training on relaxation techniques to cope with panic attacks, counseled and given psychological support. Psychological and social support to patient and family.	Anxiolytics Morphine 2.5 mg 6 hourly	Breathlessness improved, panic attacks were minimized.
Case 3	Taught controlled breathing exercises, pursed lip breathing, hand held fan, relaxation techniques, reassurance and counselling, referred to pulmonary rehabilitation programme. Psychological support.	Optimized the COPD medications	Reduced number of recurrent hospital admissions, mood was elevated, able to enjoy leisure activities.
Case 4	Psychological support to patient and family, discussion about prognosis and care plan, reassurance	Optimized the cardiac medications, Oral morphine 2 mg 8 hourly titrated up to oral morphine 5 mg 8 hourly	Mobilized without oxygen, able to get done her self-care, mood was elevated. Reduced the number of hospital admissions.
Case 5	Psychological support to patient and family. Referral to Consultant Psychiatrist.	Oral morphine SR 10 mg 12 hourly Optimized the cardiac medications Anti-depressants	Improvement in mood mobilized without oxygen, managed to get done self-care without support, reduced number of hospital admissions.
Case 6	Counseled	Oral morphine 2.5 mg 8 hourly Optimized cardiac medications	Reduced the number of hospital admissions, was able to mobilize without oxygen and can get done selfcare without support.

Management of thinking cycle

Anxiety and depression are associated with poor quality of life in Palliative care setting.[8] Anxiety, fear and panic attacks are associated with breathlessness[9] and contributes significantly to the thinking cycles. Breathing control, relaxation techniques and psychological support improves the breathlessness, performance state and physical and emotional control of patients.[10] Use of a fan with cool air blowing to the face was studied with effective results.[11] Benzodiazepines are used as a second or third-line treatment in addition to non-pharmacological measures and morphine.[12]

In the first patient the functioning cycle was dominant; in the second case the most affected domain was the thinking cycle and it adversely affected the patient as well as the family. The third patient had mainly the breathing cycle affected. All three patients who had end stage cardiac failure were having some degree of anxiety with episode of exacerbations. With the improvement of breathlessness and ability to complete activities of daily life and low dose morphine, they settled.

Management of breathing cycle: Deconditioning chronic breathlessness

In clinical practice, clinicians need to view breathlessness in the context of full patient experience.[13] Training on breathing control techniques, progressive muscle relaxation techniques, distraction exercises, breathing and relaxation techniques, coping strategies and walking aids help in management of functional and social activities. These strategies have proven beneficial benefit.[14,15]

In case 1, the patient was breathless at rest with a dyspnea scale mMRC grade 4. His upper and lower limbs were weak, stiff and chair bound. During the course of limited pulmonary rehabilitation, he was trained on upper and lower limb muscle strengthening exercises. With that he was able to mobilize independently with the oxygen stand with wheels. His quality of life improved with time, reducing the frequency of panic attacks and improving mood.

In case 3, pulmonary rehabilitation program was introduced at the beginning. He was reintroduced to the pulmonary rehabilitation program for the improvement of functioning cycle and given psychological support. Breathlessness was managed by optimizing treatment of COPD. Use of morphine and psychological support significantly improved his quality of life and decreased the number of hospital admissions.

For patients with refractory dyspnea, opioids are a safe and effective treatment[8] and all the patients were prescribed morphine to improve the breathing cycle by reducing the perception of breathlessness. Benefits of morphine was first evident by systematic analysis in 2002 for symptom control of breathlessness.[16,17] A subsequent systematic analysis supported more on the benefit as well as the safety.[14] There is evidence that morphine is beneficial in managing breathlessness in end stage cardiac failure as well.[15] There was a significant improvement of breathlessness in all 6 patients after commencement of morphine and mobility was improved significantly in all three patients with heart failure and in the patient with COPD. Quality of life was improved in all 6 patients.

Management of rehabilitation depend on goals of care in each individual. For example, the patients who were having cardiac failure were too ill even for limited cardiac rehabilitation. The non-pharmacological management of patients with advanced respiratory diseases were discussed in the interdisciplinary team meetings and individual care plans were set up.

At a practice level, identifying which “vicious circle” is the strongest driver of breathlessness helps to target the initial treatment and listening to the patient’s experience helps to identify their triggers. Educating the patient and the family to understand the genesis of breathlessness helps them to overcome misconceptions and emotions.[7] Introducing psychological, and behavioral interventions help to cope better with the situation leading to improvement in breathlessness, motivation, and cheerfulness.

The use of low dose morphine significantly improved breathlessness in all patients, and as a result, the mobility and independence also improved in varying levels in individual patients. The anxiolytics were useful to manage anxiety and panic attacks. Antidepressants were helpful in some patients in elevation of mood and to improve compliance and improve quality of life.[18]

Non-pharmacological measures such as a handheld fan, breathing exercises, relaxation techniques, coping mechanisms, upper body exercises, walking aids were helpful in our patients to improve breathing.

Learning points

Goals of care for patients with refractory breathlessness in end stage diseases depend on individual patient preferences and stage of the underlying illness trajectory. The treating team has to ensure that the treatment of underlying disease is

optimized and all treatable and reversible causes which may contribute to worsening breathlessness are addressed. Goals need to be reassessed frequently with the progression of the underling illness and other co-morbidities.

BTS model targets different components of the complex interventions effectively and this article addresses the cultural adaptation and use of it in the management of patients in the Sri Lankan setting. It is evident that there is a high level of distress, physical limitations, and psychosocial burden leading to poor quality of life of those who are living with chronic breathlessness. As illustrated in the above cases, assessment of three domains of breathlessness and identification of the strongest driver and targeting the treatment strategy for individual patient is effective in providing relief and improving quality of life.

Conclusions

This paper describes the management of breathlessness by a non-oncology team that was formed to provide palliative care in a resource limited setting in Sri Lanka. The case series shows the utility of a simple framework (i.e. three cycles), use of morphine and the importance of rehabilitation.

Authors' contributions

RU, KR, HC and JZ conceived the original study idea and contributed to research designing. TMA carried out data collection. RU and EE contributed to the data analysis and applying the BTF Model. RU, EE and SJ contributed to literature review and drafting the paper. All authors read and approved the final manuscript.

References

1. Dyspnea Mechanisms, assessment, and management: a consensus statement. American Thoracic Society. *Am J Respir Crit Care Med* 1999; **159** (1): 321-40. doi: 10.1164/ajrccm.159.1.ats898.
2. Yohannes AM. Palliative care provision for patients with chronic obstructive pulmonary disease. *Health Qual Life Outcomes*. 2007; **5**: 17. https://doi.org/10.1186/1477-7525-5-17.
3. Spathis A, Booth S, Moffat C, et al. The Breathing, Thinking, Functioning clinical model: a proposal to facilitate evidence-based breathlessness management in chronic respiratory disease. *npj Prim Care Resp Med* 2017; **27**. https://doi.org/10.1038/s41533-017-0024-z
4. Parshall MB, Schwartzstein RM, Adams L, et al. An official American Thoracic Society statement: update on the mechanisms, assessment, and management of dyspnea. *Am J Respir Crit Care Med*. 2012; **185**(4): 435-52.
5. Keijzers G, Kelly A, Cullen L, et al. Heart failure in patients presenting with dyspnoea to the emergency department in the Asia Pacific region: an observational study. *BMJ Open* 2017; **7**: e013812. doi: 10.1136/bmjopen-2016-013812
6. Tanaka K, Akechi T, Okuyama T. Impact of dyspnea, pain, and fatigue on daily life activities in ambulatory patients with advanced lung cancer. *J. Pain Symptom Manage* 2002; **23**: 417-23.
7. Booth S, Johnson MJ. Improving the quality of life of people with advanced respiratory disease and severe breathlessness. *Breathe* 2019; **15**: 198-215. doi: 10.1183/20734735.0200-2019
8. Smith EM, Gomm SA, Dickens CM. Assessing the independent contribution to quality of life from anxiety and depression in patients with advanced cancer. *Palliat Med*. 2003; **17**(6): 509-13.
9. Nardi AE, Freire RC, Zin WA. Panic disorder and control of breathing. *Respir Physiol Neurobiol*. 2009; **167**: 133-43.
10. Bredin M, Corner J, Krishnasamy M, et al. Multicentre randomised controlled trial of nursing intervention for breathlessness in patients with lung cancer. *BMJ*. 1999; **318**: 901.
11. Wong SL, Leong SM, Chan CM, et al. The Effect of Using an Electric Fan on Dyspnea in Chinese Patients with Terminal Cancer. *Am J Hosp Palliat Care*. 2017; **34**(1): 42-6. doi: 10.1177/1049909115615127
12. Ekström M , Nilsson F , Abernethy AA , et al. Effects of opioids on breathlessness and exercise capacity in chronic obstructive pulmonary disease. A systematic review. *Ann Am Thorac Soc*. 2015; **12**(7): 1079-92. doi:10.1513/AnnalsATS.201501-034OC
13. Johnson MJ, McDonagh TA, Harkness A, McKay SE, Dargie HJ. Morphine for the relief of breathlessness in patients with chronic heart failure-a pilot study. *Eur J Heart Fail*. 2002 ; **4**(6): 753-6. doi: 10.1016/s1388-9842(02)00158-7.
14. Simon ST, Higginson IJ, Booth S, et al. Benzodiazepines for the relief of breathlessness in advanced malignant and non-malignant diseases in adults. *Cochrane Database Syst Rev* 2016; **10**: CD007354.
15. Abernethy AP, Wheeler JL. Total dyspnoea. *Curr Opin Support Palliat Care*. 2008; **2**(2): 110-3. doi: 10.1097/SPC.0b013e328300cad0.
16. Crombeen AM, Lilly EJ. Management of dyspnea in palliative care. *Curr Oncol*. 2020; **27**(3): 142-5. doi:10.3747/co.27.6413
17. Jennings AL, Davies AN, Higgins JPT, et al. A systematic review of the use of opioids in the management of dyspnoea. *Thorax* 2002; **57**: 93944. doi: 10.1136/thorax.57.11.939
18. Bausewein C, Booth S, Gysels M, Higginson IJ. Non-pharmacological interventions for breathlessness in advanced stages of malignant and non-malignant diseases. *Cochrane Database Syst Rev*. 2013; **11**: CD005623. doi: 10.1002/14651858.CD005623.pub3