

A retrospective study of breathlessness supportive therapy on chronic refractory breathlessness in a palliative care unit

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ABSTRACT

Introduction: Chronic refractory breathlessness is a debilitating symptom which negatively affects quality of life with profound impact on physical and psychosocial functioning of patients and/or carers. Multidisciplinary based interventions which focus on non-pharmacological approach have shown to be effective. We developed a breathlessness intervention service called breathlessness supportive therapy (BST) in a palliative care unit with limited resources. The aim is to evaluate the feasibility of developing a BST service and to study the characteristics and outcome of patients with chronic refractory breathlessness.

Materials and Methods: This is a retrospective study of patients with chronic refractory breathlessness and Modified Medical Research Council (mMRC) dyspnoea scale grade ≥ 2 who attended the BST clinic over 1 year period. BST consists of two clinic sessions 2 weeks apart. Data was retrieved from patients' medical notes and analysis done using Microsoft Excel.

Results: A total of 21 patients were identified. Median age was 69 years with 52% of females. 72% had non-malignant diagnoses. Median Charlson's Comorbidity Index score was 6.5. Median mMRC dyspnoea scale was 3. 47.6% had long term oxygen usage. Median Australian Karnofsky Performance Scale (AKPS) was 65 and the median baseline breathlessness visual analogue scale (VAS) was 2. 62% completed two sessions, the remaining 38% completed only one session. Mean time from BST intervention to death was 18.26 weeks, median was 22 weeks. 72% died at home, whilst 28% died in the hospital. All the patients scored 4 (somewhat agree) and 5 (strongly agree) on the overall feedback score.

Conclusions: Development of a breathlessness intervention service is feasible in a resource limited setting and generally accepted by most patients. More research and prospective studies are needed to evaluate the effectiveness of BST in the future.

KEYWORDS:

Chronic refractory breathlessness, palliative care, breathlessness intervention service, breathlessness supportive therapy, nonpharmacological intervention

INTRODUCTION

Chronic refractory breathlessness is defined as breathlessness at rest or on minimal exertion that persists despite optimal treatment of underlying causes.¹ Breathlessness is a debilitating symptom that leads to suffering and negatively affects quality of life with profound impact on physical and psychosocial functioning of patients and/or carers.² Two large whole-of-population surveys done suggest that the prevalence of chronic breathlessness in the community is 9 to 11%.^{3,4} Prevalent aetiologies include chronic obstructive pulmonary disease (up to 95%), advanced cancer (up to 90%), heart failure (up to 88%) and end stage renal failure.^{5,6}

The breathing, thinking and functioning model proposed by Spathis et al postulates that the problems arising from one or more of these domains contribute to the generation of breathlessness. For example, a person with chronic breathlessness may have an ineffective breathing pattern with increased work of breathing (breathing domain) which can lead to anxiety and/or fear (thinking domain), perpetuating the symptom of breathlessness. Patient may become socially isolated with reduced physical activity, leading to cardiovascular and muscle deconditioning, further worsening breathlessness (functioning domain).⁷ These domains may co-exist and interconnect. Hence, identification of the domain which predominantly causes breathlessness helps clinicians focus on the management strategies to break the vicious cycle.

Oral or parenteral opioids can improve refractory breathlessness however the quality of evidence is low.⁸ Nonpharmacological approaches such as handheld fans, breath training, pulmonary rehabilitation, cognitive behavioural therapy, mindfulness therapy, exercise and self-management strategies have been shown to improve breathlessness.⁷⁻¹⁰ There is emerging evidence of multidisciplinary based interventions shown to improve breathlessness. The Cambridge breathlessness intervention service is effective in reducing patients' distress and fear/worry due to breathlessness, as well as demonstrating cost effectiveness in the management of breathlessness.¹¹ An integrated service including palliative care, respiratory medicine, physiotherapy and occupational therapy showed that patients with chronic refractory breathlessness report improved breathlessness in both cancer and non-cancer groups.¹²

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Table I: Patient characteristics

Patient characteristics	
Variables	
Age, median (IQR)	69 (57.5 – 74.25)
Gender	
Male, n (%)	10 (47.6%)
Female, n (%)	11 (52.4%)
Diagnosis	
Malignancy, n (%)	6 (28.6%)
COPD, n (%)	6 (28.6%)
Heart failure, n (%)	6 (28.6%)
ESRD, n (%)	1 (4.76%)
Pulmonary hypertension, n (%)	1 (4.8%)
Pulmonary fibrosis	1 (4.8%)
CCI, median (IQR)	6.5 (4.25-8)
0-3, n (%)	1 (4.8%)
4-6, n (%)	7 (33.3%)
7-9, n (%)	6 (28.8%)
≥10, n (%)	1 (4.8%)
Missing data, n (%)	6 (28.6%)
mMRC dyspnoea scale, median (IQR)	3 (2-3.75)
2, n (%)	5 (23.8%)
3, n (%)	5 (23.8%)
4, n (%)	5 (23.8%)
Missing data, n (%)	6 (28.6%)
Oxygen use	
Yes, n (%)	10 (47.6%)
No, n (%)	5 (23.8%)
Missing data, n (%)	6 (28.6%)
AKPS, median (IQR)	65 (60-70)
40, n (%)	1 (4.8%)
50, n (%)	2 (9.5%)
60, n (%)	6 (28.6%)
70, n (%)	4 (19%)
80, n (%)	2 (9.5%)
Missing data, n (%)	6 (28.6%)
Baseline VAS score, median (IQR)	2 (2-4.5)
1, n (%)	2 (8.3%)
2, n (%)	3 (14.3%)
3, n (%)	1 (4.8%)
4, n (%)	1 (4.8%)
5, n (%)	2 (9.5%)
6, n (%)	1 (4.8%)
Missing data, n (%)	11 (52.4%)

IQR: Interquartile Range; COPD: Chronic Obstructive Pulmonary Disease; ESRD: End Stage Renal Disease; CCI: Charlson Comorbidity Index; mMRC: Modified Medical Research Council; AKPS: Australia-modified Karnofsky Performance Scale; VAS: Visual Analogue Score

To our knowledge, there is no dedicated multidisciplinary breathlessness intervention service in Malaysia. The exact prevalence of chronic refractory breathlessness in Malaysia is unknown. Based on an Asia-based population survey amongst individuals above 40 years of age, the estimated prevalence of chronic obstructive pulmonary disease (COPD) is 4.7%, and 12.5% has severe symptomatic phenotype.¹³ In addition, with increasing cancer incidence annually and increasing percentage (89.5 to 93%) of late-stage lung cancer on diagnosis, patients with refractory breathlessness is expected to rise.^{14,15}

The Palliative Care Unit in Hospital Raja Permaisuri Bainun has developed a breathlessness supportive therapy (BST) outpatient service which incorporates non-pharmacological interventions and provides an individualised breathlessness action plan. The aims of this study are to assess the feasibility and acceptability of the BST to patients and evaluate outcomes of the service. This can help guide us to develop

better services in the future to manage patients with chronic refractory breathlessness.

MATERIALS AND METHODS

Study Design

We conducted a retrospective cohort analysis of patients with chronic refractory breathlessness who attended the BST clinic in a single Palliative Care Unit at Hospital Raja Raja Permaisuri Bainun, Ipoh, Malaysia. This is a descriptive study. We obtained ethics approval from the Medical Ethics and Research Committee, Ministry of Malaysia (NMRR ID-23-01300-PLD).

Study Population

All adult patients ≥ 18 years with chronic refractory breathlessness and mMRC dyspnoea scale grade ≥ 2 who attended the BST from 1st January 2022 to 31st December 2022 were included in the study.

Table II: Outcomes of BST intervention.

Outcomes	n (%)
Number of patients, n (%)	21 (100%)
Completed 2nd sessions, n (%)	13 (61.9%)
Only completed 1st session, n (%)	8 (38.1%)
Clinical outcome (n = 21)	
Died, n (%)	18 (85.7%)
Alive, n (%)	3 (14.3%)
Reason for not completing 2nd session (n = 8)	
Too unwell, n (%)	5 (62.5%)
Not interested, n (%)	1 (12.5%)
Died, n (%)	1 (12.5%)
Logistics, n (%)	1 (12.5%)
Hospital admission post BST (n = 21)	
Yes, n (%)	7 (33.3%)
No, n (%)	13 (61.9%)
Missing data, n (%)	1 (4.8%)
Time from BST intervention to death (weeks)	
Median, weeks (IQR)	22 (8.5-26)
Place of death (n = 18)	
Home, n (%)	13 (72%)
Hospital, n (%)	5 (28%)

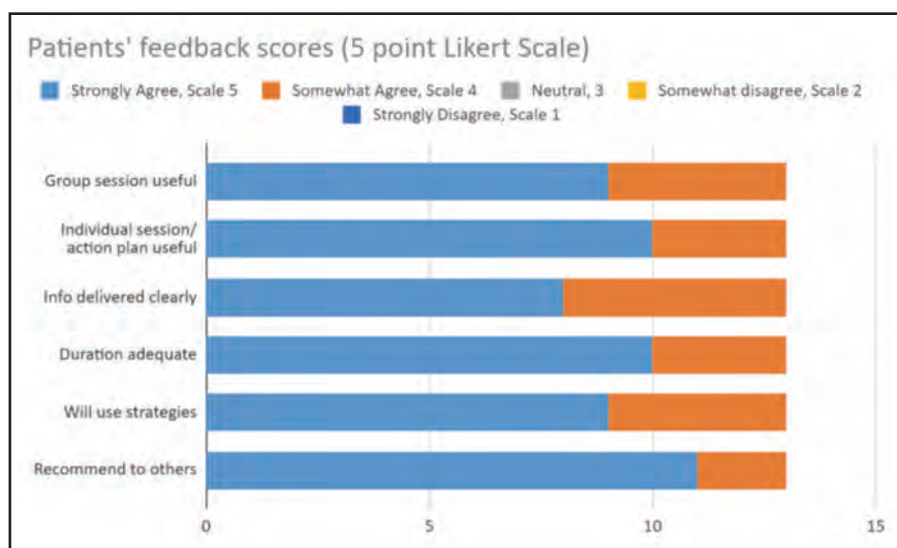


Fig. 1: Patients' feedback score for BST.

Data Collection

Data was retrieved from the patients' medical records which are stored in the medical records department. As medical records were kept in a physical folder, data from the medical records were transcribed into a password protected computer. Baseline data collected from the first BST clinic visit included demographics (age and gender); diagnosis, comorbidities; Australia-modified Karnofsky performance scale (AKPS); mMRC dyspnoea scale, oxygen use, and baseline breathlessness visual analogue score (VAS). Charlson comorbidity index (CCI) is used to categorise comorbidities of patients by the sum of all the individual scores for every comorbidity score assigned.

Outcome data extracted include BST clinic completion rates, clinical outcome, post BST intervention breathlessness VAS scores, reasons for not completing two sessions, feedback scores, number of hospital admission post BST intervention. Feedback scores are recorded using a 5-point Likert scale of 1 to 5.

Data Analysis

We used Microsoft Excel to perform summary statistics in the format of mean and standard deviation (SD), median and interquartile range (IQR). As the number of patients is too small and with significant missing data, further statistical analysis is not carried out as it is likely to be insignificant.

RESULTS

A total of 21 patients attended BST with chronic refractory breathlessness and mMRC grade ≥ 2 from 1st January 2022 to 31 December 2022. 52% were females. The median age was 69 years (IQR: 57 to 74). Malignancy accounts for 28.6% of primary diagnosis. Non-malignant diagnoses such as COPD, heart failure end stage renal disease, pulmonary fibrosis and pulmonary hypertension account for the remaining 71.4%. The median CCI score was 6.5 (IQR: 4.25 to 8). Median mMRC dyspnoea scale was 3 (IQR: 2 to 3.75). 47.6% have long term oxygen usage. Median AKPS score was 65 (IQR: 60 to 70) and the median baseline breathlessness VAS score was

2 (IQR: 2 to 4.5). Baseline patient characteristics are shown in Table I.

Outcomes

A total of 62% of patients completed two sessions, the remaining 38% completed only the first session. For the eight patients who did not complete the 2nd session, five (62%) were too unwell to participate, one (12%) was not interested, one (12%) died and one (12%) was unable to attend due to logistic reasons. 18 (86%) patients died and three (14.3%) remained alive during the time of writing.

After BST intervention, 13 patients (62%) did not require hospital admission. Of the seven (33%) patients who had hospital admission, one (14%) had only one admission, five (72%) had two admissions and one (14%) had five admissions. Only one remains alive at the time of data collection, amongst those who had no hospital admission post BST intervention. The mean time from BST intervention to death was 18.26 weeks (SD: 11.99), median time was 22 weeks (IQR: 8.5 to 26). 13 (72%) died at home, whilst five (28%) died in the hospital.

We were only able to extract data on post BST intervention breathlessness VAS score for seven patients (33%). Two patients showed improvement with change of VAS -2 where both had baseline VAS score of 5 and 6 respectively. Three had no change in VAS score, although they had baseline VAS score of less than 2. One had a worsening VAS score from 3 to 4 post intervention. No adverse events were recorded during BST clinic.

All the participants responded with scores of 4 (somewhat agree) and 5 (strongly agree) to the feedback scores on BST intervention. Among questions asked on feedback form include: 1) group sessions useful 2) Individual session/action plan useful; 3) info delivered clearly; 4) Duration adequate; 5) will use strategies and 6) recommend to others. None of the participants scored 3 or less on any of the category.

DISCUSSION

Our study showed that it is feasible to initiate a breathlessness intervention service in a resource limited setting. By adopting a multi-disciplinary approach and focusing on non-pharmacological interventions to manage breathlessness, most patients find that BST clinic to be helpful. Majority of patients (62%) were able to complete two sessions. To our knowledge, the BST clinic is the first breathlessness intervention service in the country, especially in a locality with limited resources.

Each BST clinic session is run by a dedicated palliative care medical officer and an occupational therapist. The role of the medical officer is to perform clinical assessment during BST clinic, while the occupational therapist provides education and training on non-pharmacological strategies in managing breathlessness. No additional staff members were recruited, or extra funds required to run the BST clinic. The BST clinic is conducted in an existing PCU outpatient building, hence no new infrastructure is required. Inpatient referrals come from the palliative care ward and other departments where the specialist palliative care team

provides consultative service. Outpatient referrals are from the palliative care clinic. Patients with chronic refractory breathlessness with mMRC dyspnoea scale grade ≥ 2 are considered for referral to the BST clinic, regardless of diagnosis. In the first BST clinic session, patients undergo initial clinical assessment followed by a group session on non-pharmacological interventions. An information booklet containing information on interventions such as breathing techniques, breathing positions, energy conserving strategies and thought management strategies is given to patients who are advised to practise twice daily for 10 minutes based on a practice schedule. Patient is then reassessed individually 2 weeks later, and a personalised breathlessness action plan is created.

As this is a newly developed service, all referrals are received upon assessment and deemed appropriate by the specialist palliative care team. A total of 32 referrals were recorded in 2022. There were 11 patients (34%) who were not able to attend BST clinic upon referral. Nine of them were either too ill to attend or have died prior to BST clinic appointment. This highlights the need to triage patients and improve patient selection for BST clinic in the future.

Our cohort of patients with chronic refractory breathlessness have better functional status (70% with AKPS ≥ 40) and with predominantly cardiorespiratory diagnoses (71.4%). However, due to small sample size, we were not able to adequately assess symptom burden or intensity in our study. It is postulated that breathlessness intensity in people with better functional status (AKPS ≥ 40) and with cardiorespiratory diseases in the last weeks of life.¹⁶ This indicates that our group of patients may have a more significant symptom burden and highlight the need to improve breathlessness management strategies.

Interestingly, our study shows that there is lesser hospital admission (62% not hospitalized) post BST intervention. In addition, majority of the patients died at home (72%) compared to 28% in the hospital. This may suggest that BST intervention is useful in managing breathlessness and subsequently reduce the need for acute hospital services utilisation and inpatient end of life care.

There are several limitations to our study. Firstly, this is a retrospective study and is subjected to biases associated with this study design. The sample size of the study is small and unlikely to contribute to statistically significant data. As previously mentioned, there are significant gaps in the baseline data collected especially with pre and post BST intervention breathlessness score. Hence, we are not able to measure the effectiveness of the BST intervention and study associated factors. Although we manage to show lower hospital admission and increased home deaths post BST intervention, there could be many other confounding factors that could contribute to this observation and are not included in the analysis of this study.

CONCLUSION

Multidisciplinary non-pharmacological approach to manage chronic refractory breathlessness is helpful. We have demonstrated that developing a breathlessness intervention

service is feasible in a resource limited setting. However, further prospective studies are required to measure its effectiveness.

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