

Patients' experiences of a new integrated breathlessness support service for patients with refractory breathlessness: Results of a postal survey

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Charles C Reilly¹, Claudia Bausewein^{1,2}, Caty Pannell¹,
John Moxham³, Caroline J Jolley³ and Irene J Higginson¹

Abstract

Background: We developed a new single point of access to integrated palliative care, respiratory medicine and physiotherapy: the breathlessness support service for patients with advanced disease and refractory breathlessness. This study aimed to describe patients' experiences of the service and identify the aspects valued.

Design: We attempted to survey all patients who had attended and completed the 6-week breathlessness support service intervention by sending them a postal questionnaire to self-complete covering experience, composition, effectiveness of the BSS and about participation in research. Data were analysed using descriptive statistics and thematic analysis of free text comments.

Results: Of the 70 postal questionnaires sent out, 25 (36%) returned. A total of 21 (84% (95% confidence interval: 69%–98%)) responding patients reported that they definitely found the breathlessness support service helpful and 13 (52% (95% confidence interval: 32%–72%)) rated the breathlessness support service as excellent. A total of 21 (84% (95% confidence interval: 69%–98%)) patients reported that the breathlessness support service helped with their management of their breathlessness along with additional symptoms and activities (e.g. mood and mobility). Four key themes were identified: (1) personalised care, (2) caring nature of the staff, (3) importance of patient education to empower patients and (4) effectiveness of context-specific breathlessness interventions. These were specific aspects that patients valued.

Conclusion: Patients' satisfaction with the breathlessness support service was high, and identified as important to this was a combination of personalised care, nature of staff, education and empowerment, and use of specific interventions. These components would be important in any future breathlessness service.

Keywords

Palliative care, breathlessness support service, breathlessness, chronic obstructive, pulmonary disease, cancer

What is already known about this topic?

- Refractory breathlessness is common in advanced disease;
- Breathlessness services have been developed to help manage this disabling symptom, but until recently, the evidence to support such services has been limited;
- Recently, we have demonstrated that our integrated palliative care, respiratory medicine and physiotherapy breathlessness support service (BSS) improves patients mastery over their breathlessness.

¹Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King's College London, London, UK

²Department for Palliative Medicine, Munich University Hospital, Munich, Germany

³Department of Asthma, Allergy and Respiratory Science, King's College London, London, UK

Corresponding author:

Charles C Reilly, Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King's College London, London, UK, SE5 9PJ.
Email: charles.c.reilly@kcl.ac.uk

What this paper adds?

- Patient satisfaction with the BSS was high, with many of the patients rating the care they received as excellent.
- Patient free text comments identified four key themes which they valued: (1) personalised care, (2) caring nature of the staff, (3) importance of patient education to empower patients, (4) effectiveness of context-specific breathlessness interventions.
- In addition to providing breathlessness support, the BSS provided information on other symptoms, e.g. immobility, pain and available services, e.g. pulmonary rehabilitation and community support.

Implications for practice, theory or policy.

- These findings help to understand how the BSS may be working and would be key components in any attempt to reproduce the BSS

Introduction

Refractory breathlessness, that is, breathlessness that continues despite optimal treatment of the underlying condition, is a common incapacitating problem in the later stages of many diseases.¹ Studies have shown that 94% of the patients with chronic lung disease,² 78% of those with lung cancer² and more than 50% of the patients with heart disease³ suffer from breathlessness in the last year of life.

Multidisciplinary rehabilitation programmes, incorporating exercise training and education, have been shown to reduce breathlessness and improve exercise capacity in chronic obstructive pulmonary disease (COPD), heart failure and cancer.^{4–6} However, patients with advanced disease are often too ill to attend pulmonary rehabilitation programmes. Building upon evidence and NICE guidance, breathlessness services have been successfully developed, and evidence suggests that such services are successful in the palliation of this disabling symptom.^{4,6–8}

Unfortunately, accessibility to breathlessness services is not uniform across the National Health Service (NHS). In response to this unmet need of our local patient population, we developed a new single point of access to integrated palliative care, respiratory medicine and physiotherapy: the breathlessness support service (BSS). Our randomised controlled trial (RCT) comparing the BSS to standard care demonstrated that patients who received the BSS had, at 6 weeks, significantly improved breathlessness mastery, quantified using the Chronic Respiratory Questionnaire (CRQ).⁹

Patient experience and satisfaction are important in assessing quality of health care and can be predictive of subsequent improvements in health.¹⁰ This study aimed to describe patients' experiences of the BSS and to understand what aspects influenced their satisfaction with it.

Methods**Design**

The study design was a self-complete postal questionnaire survey of patients who had accessed the BSS. Ethics approval for the study was obtained from the King's College Hospital Ethics Committee (Ref. 10/H0808/17).

Setting

Data were collected as part of a randomised controlled parallel-group, pragmatic, single-blind fast-track trial, investigating the effectiveness of the BSS for the palliation of breathlessness.⁹ Patients were referred to the BSS by health professionals in primary and secondary care. Patients suffered from refractory breathlessness despite optimal medical management, as deemed by the referring health-care professional. All patients were offered access to the BSS.⁹ Details of the trial have been published elsewhere.⁹

Sample

A total of 105 patients consented to enrol in the RCT, of which 75 accessed the BSS (fast-track = 53, delayed entry = 22) and were included in this nested study.

The breathlessness support service (BSS)

The BSS is distinct from previous services;^{5,11} it incorporates respiratory expertise, widens the professionals providing care and comprises an outpatient clinic with two appointments interspersed with a home visit. At the first clinic visit, patients were assessed by respiratory medicine and palliative care clinicians, and an individualised plan of treatment was agreed. Patients received a breathlessness pack with information, management and pacing guidance, a poem (to help breathing and relaxation during crises), a hand-held fan and/or water spray and an individualised crisis plan. A home assessment after 2–3 weeks was done by a respiratory physiotherapist and/or occupational therapist that developed a tailored programme based on the domestic situation of the patient. If needed, they referred to additional services such as pulmonary rehabilitation and social work. After the second and final clinic visit (at around 4 weeks after initial assessment) further individualised actions and a discharge plan were agreed. Summaries of both clinic visits were sent to the individual, with a copy to their GP and referring health professional. Full details are published in the protocol and trial results.^{12,13}

Questionnaire

A self-complete postal questionnaire covering experience, composition, effectiveness of the BSS and about

Table 1. Baseline characteristics of patients who accessed the BSS, those who did not return (*non-respondents*) and those who did returned the postal questionnaire (*respondents*).

	Patients who accessed and completed the 6-week BSS intervention	BSS patients who did not return the postal questionnaire (<i>non-respondents</i>)	BSS patients who returned the postal questionnaire (<i>respondents</i>)
n	75	50	25
Age (years) ^a	66 (40–88)	70 (40–88)	63 (51–81)
Sex (male: female)	45:30	29:21	16:9
Diagnosis (n, %)			
COPD	39 (52)	25 (50)	14 (56)
Cancer	15 (20)	9 (18)	6 (24)
ILD	13 (17)	9 (18)	4 (16)
HF	5 (7)	4 (8)	1 (4)
Other	3 (4)	3 (6)	
Carer present (yes: no)	52:23	37:13	15:10
FEV ₁ %predicted ^a	47 (12–106)	53 (14–106)	37 (12–92)
VC%predicted ^a	60 (12–116)	57 (12–116)	61 (13–114)
SaO ₂ (%) ^a	95 (80–98)	95 (80–98)	94 (84–97)
NRS breathlessness average 24 h (0–10) ^{1a}	6 (0–10)	6 (0–10)	6 (3–10)
NRS breathlessness worst at rest (0–10) ^{1a}	6 (0–10)	6 (0–10)	6 (0–10)
NRS breathlessness on exertion (0–10) ^{1a}	8 (4–10)	8.5 (4–10)	8 (6–10)

BSS: breathlessness support service; COPD: chronic obstructive pulmonary disease; ILD: interstitial lung disease; HF: heart failure; FEV₁: forced expiratory volume in 1 s; VC: vital capacity; NRS: numerical rating scale; I: high score worse.

^aData expressed as median and range.

participating in research was used. The questionnaire built on earlier service evaluations. We sent one reminder, 6 weeks after sending out the initial questionnaire.

Questions were presented in the form of short statements, to which patients were asked to rate their level of agreement (both in the positive and negative directions). In addition, there were free text boxes for patients to comment on any aspect of the service (a copy of the questionnaire is available in the online supplement (S1)).

Procedures

The BSS questionnaire, along with a returnable stamped addressed envelope to the BSS research team, was sent to all patients after their final visit to the BSS.

Data analysis

The data collected from the returned BSS evaluation questionnaires were entered into a database using the Statistical Package for Social Science for Windows, version 19 (SPSS Inc., Chicago, IL). Data were analysed using descriptive statistics. Patients were also given the opportunity to comment on specific aspects of the BSS. These free text comments were extracted and transcribed, and themes were identified by thematic analysis. Subsequently, both the free text comments and themes were reviewed (I.J.H./C.B.), and following discussion, refinement and consensus, the final themes were agreed.

Results

A total of 70 postal questionnaires were sent out (5 were not sent out due to an administrative error). A total of 25 patients (36%) returned the questionnaire. The baseline characteristics of patients who accessed the BSS, those who did not return (*non-respondents*) and those who returned the postal questionnaire (*respondents*) are summarised in Table 1.

Patient satisfaction with the BSS

A total of 21 (84% (95% confidence interval (CI): 69%–98%)) responding patients reported that they definitely found the BSS helpful, with 13 (52% (95% CI: 32%–72%)) patients rating the BSS as excellent. In addition, 24 (96% (95% CI: 88%–104%)) patients reported that they found the joint physiotherapy and occupational therapy home visit useful.

The majority of patients reported that they would not change the composition of the BSS, and they valued the holistic, friendly nature of the service. One patient suggested that in addition to the current BSS: ‘Self-help or exercise groups for breathlessness patients and carers may be helpful, and promote self-management’ (65-year-old woman with COPD).

Another patient suggested that the following question should be incorporated into the BSS consultations: ‘Is there anything you cannot discuss with your family that

you would like to talk about today?’ (69-year-old woman with COPD).

A total of 17 (68% (95% CI: 50%–86%)) patients reported that they did not have to wait to see a health-care professional at the BSS clinic, 5 (20% (95% CI: 4%–36%)) had to wait but reported that the wait was shorter than their regular clinic wait time and 3 (12% (95% CI: –1% to 25%)) reported that their waiting time was long but similar to their previous experience in other services. All patients reported that they would recommend the service to someone else (Table 2).

Benefits of the service

A total of 21 (84% (95% CI: 69%–98%)) patients reported that the BSS helped with their management of their breathlessness along with additional symptoms and activities (e.g. mood and mobility) summarised in Figure 1. A total of 21 (84% (95% CI: 69%–98%)) patients reported that the BSS provided them with additional information and support with regard to additional services (e.g. access to social services and referral to pulmonary rehabilitation), which is summarised in Figure 2.

Interventions provided

The majority of patients reported that information provided; positions to relieve breathlessness and managing breathlessness, the hand-held fan and discussions about crisis management were the most helpful interventions offered at the clinic visit. With regard to the joint physiotherapy and occupational therapy home visit, patients reported that breathing exercises and relaxation techniques were the most helpful (Table 2).

Free text comments

From the free text component of the questionnaire, four key themes were identified as follows:

1. Personalised care
2. Caring nature of the staff
3. Importance of patient education to empower patients
4. The effectiveness of context-specific breathlessness interventions

Illustrative quotes are provided in Table 3.

Participation in research

When the patients were asked about participating in the research, 23 (92% (95% CI: 81%–103%)) patients said that they would definitely participate in the research again, the remaining 2 patients reported that they did not know if

they would. A total of 18 (72% (95% CI: 54%–90%)) patients reported that they felt their involvement in research was a worthwhile experience.

Discussion

The main finding of this study is that the BSS was well accepted by patients; just over half of the respondent rated the care they received by the BSS as excellent. Patients reported that the BSS, through its holistic approach to the management of breathlessness, not only provided them with skills and interventions to better manage their breathlessness but also acknowledged additional coexisting symptoms, for example, pain and immobility. Moreover, the BSS provided patients with additional support and information regarding additional supportive services e.g., community palliative care and pulmonary rehabilitation.

Significance of the findings

Although this study was not designed to identify the precise BSS components that helped patients, themes identified from the free text comments and answers provided specific to the BSS interventions suggest a combination of management strategies (both education of patients and use of specific therapies) combined with a person-centred approach applied by caring and skilled staff, of the BSS. Specific components highlighted by patients included breathing exercises, education, the fan, discussions around crisis management, pacing, talking and active listening by the BSS team.

Participants identified that their treatment as individuals, coupled with the (perceived) caring nature of BSS staff, made them feel comfortable and confident (Table 3). This is a similar finding to that reported by Preston et al.,¹⁴ where patients felt both more comfortable and more confident with caring staff who were responsive to their individual needs, whereas patients reported feelings of distress (such as anxiety, unimportance and powerlessness) when care was perceived as not being personalised. The focus of management on individual concerns also responds to findings that individual breathlessness trajectories do not reflect summary trajectories.¹⁵

In the context of advanced disease, breathless patients are likely to feel little control over their situation and future.^{16,17} Offering ways that they can personally make life better for themselves is vital.⁷ Patients may command a sense of control in varying ways: regaining control during breathlessness episodes, having a personal role in their symptom management and feeling more in control in the wider illness context. Increased control has been previously demonstrated to be associated with reduced distress due to breathlessness.^{4,5,8,18} An increased perception of control and understanding of their breathlessness symptom

Table 2. Patient satisfaction and experience of the BSS.

	Yes, definitely, n (%; 95% CI)	Yes, to some extent, n (%; 95% CI)	No, n (%; 95% CI)	Not answered, n (%; 95% CI)
Contact with the BSS				
Did you find the BSS outpatient visits helpful?	21 (84, 69 to 98)	4 (16, 2 to 30)	–	–
Did the BSS provide you with an opportunity to talk about things you wanted to discuss?	23 (92, 81 to 103)	1 (4, –4 to 12)	–	1 (4, –4 to 12)
Did you find the BSS physiotherapy and occupational home visit helpful?	18 (72, 54 to 90)	6 (24, 7 to 41)	–	1 (4, –4 to 12)
Did the home BSS home visit give you the opportunity to talk about things you wanted to discuss?	21 (84, 69 to 98)	4 (16, 2 to 30)	–	–
General views on the service				
Did the BSS listen to you carefully?	24 (96, 88 to 104)	1 (4, –4 to 12)	–	–
Did you have trust and confidence in the BSS team?	25 (100, 100)	–	–	–
Did the BSS treat you with respect and dignity?	25 (100, 100)	–	–	–
Were you given enough time to discuss your condition and treatment?	24 (96, 88 to 104)	1 (4, –4 to 12)	–	–
Were you given the chance to express your views during the BSS consultations?	23 (92, 81 to 103)	2 (8, –3 to 19)	–	–
Did you find the BSS consultations helpful?	24 (96, 88 to 104)	1 (4, –4 to 12)	–	–
Did you have enough say in decisions about your treatment and care?	22 (88, 75 to 101)	3 (12, –1 to 25)	–	–
Did the BSS discuss your diagnosis with you?	20 (80, 64 to 96)	2 (8, –3 to 19)	3 (12, –1 to 25)	–
	Yes, n (%; 95% CI)	Helpful, n (%; 95% CI)	Not helpful, n (%; 95% CI)	Not answered, n (%; 95% CI)
Interventions Provided				
Did the clinic visit provide you with ...? Were these useful				
BSS leaflet: breathlessness information	25 (100, 100)	16 (64, 45 to 83)	–	9 (36, 17 to 55)
BSS leaflet: managing breathlessness	25 (100, 100)	20 (80, 64 to 96)	–	5 (10, –2 to 22)
BSS leaflet: distraction techniques	23 (92, 81 to 102)	16 (70, 51 to 89)	1 (4, –4 to 12)	6 (26, –4 to 16)
BSS leaflet: positions to relieve breathlessness	25 (100, 100)	18 (72, 54 to 90)	–	7 (28, 10 to 45)
BSS leaflet: hand-held fan	25 (100, 100)	17 (68, 50 to 86)	2 (8, –3 to 17)	6 (24, 7 to 41)
Sleep hygiene fact sheet	19 (76, 59 to 93)	10 (53, 31 to 75)	6 (32, 11 to 53)	3 (16, –1 to 32)
Relaxation during crises	24 (96, 88 to 103)	15 (63, 44 to 82)	2 (8, –3 to 19)	7 (29, 11 to 47)
Hand-held fan	21 (84, 70 to 98)	14 (67, 44 to 87)	4 (19, 2 to 36)	3 (14, –1 to 29)
Water spray bottle	19 (76, 59 to 93)	6 (32, 11 to 53)	8 (42, 20 to 64)	5 (26, 6 to 48)
Breathlessness poem	25 (100, 100)	13 (52, 32 to 72)	4 (19, 2 to 36)	8 (32, 18 to 50)

(Continued)

Table 2. (Continued)

	Yes, definitely, n (%; 95% CI)	Yes, to some extent, n (%; 95% CI)	No, n (%; 95% CI)	Not answered, n (%; 95% CI)	
Discussion about crisis management	21 (84, 70 to 98)	14 (67, 47 to 87)	2 (10, -3 to 23)	5 (24, 6 to 42)	
Did the physiotherapy and occupational therapy home visit provide you with ...? Were these useful					
Breathing exercises	16 (64, 45 to 83)	14 (88, 75 to 104)	–	2 (13, -4 to 29)	
Breathlessness management	17 (68, 50 to 86)	12 (71, 49 to 93)	–	5 (29, 7 to 51)	
Relaxation techniques	13 (52, 32 to 72)	12 (92, 77 to 107)	–	1 (8, -7 to 23)	
Energy conservation information	13 (52, 32 to 72)	9 (69, 44 to 94)	–	4 (31, 6 to 56)	
Walking aids	6 (24, 7 to 41)	2 (33, -5 to 71)	–	4 (67, 29 to 104)	
Other equipment	10 (40, 21 to 59)	5 (50, 6 to 94)	–	5 (50, 6 to 94)	
	Excellent	Very good	Good	Fair	Poor
Overall assessment of the BSS					
Overall, how would you rate the care you received from the BSS?	13 (52, 32 to 72)	10 (40, 21 to 59)	2 (8, -3 to 19)	–	–
	Yes, definitely	Yes, to some extent	No	Not answered	
Would you recommend the BSS to other people in a similar situation to you?	25 (100, 100)	–	–	–	
	Yes, definitely	Yes, to some extent	No	Not answered	
Participation in research					
Did you find your involvement in research useful or helpful in any way?	18 (72, 54 to 90)	7 (28, 10 to 46)	–	–	
Did you find any of the research questions upsetting?	–	1 (4, -4 to 12)	24 (96, 88 to 104)	–	
Would you agree to participate in a research study again?	23 (92, 81 to 103)				

BSS: breathlessness support service; CI: confidence interval.

through patient education and context specific interventions were themes that emerged from the patients' free text comments about the BSS. This is supported by recommendations by Syrett and Taylor.¹⁹

The BSS did not include a core exercise component, in contrast to other breathlessness management interventions, such as those used in pulmonary rehabilitation for COPD.^{20,21} For some patients, especially those who are frail and nearing end of life, formal exercise may not be an appropriate intervention. However, some patients reported that they were provided with information or interventions to help improve muscle strength to increase mobility and function, as lower limb muscle function in patients with chronic respiratory disease is of prognostic importance.^{22,23}

For some patients breathlessness episodes are short (termed episodic) and severe with significant differences between COPD and lung cancer patients.²⁴ Episodic breathlessness is associated with panic, lack of control, helplessness experiences by both the patient and carer often resulting

in accident and emergency (A&E) attendances.^{25–27} To address this unmet need, a core intervention of the BSS was breathlessness crisis management, which patients found to be useful. This further demonstrates the holistic nature of the BSS, as breathlessness cannot be treated in isolation to its complex physiological, psychological and environmental components.

Two key points were raised by patients regarding further improvements to the service. First, with reference to the social element of the BSS, enhancement of social interaction is of great importance to participants, as illustrated by one BSS study participant, who suggested access to a local support group for patients and carers living with breathlessness to help sustain and build upon the positive effects of the BSS. Such peer-support groups have shown positive outcomes in patients with cancer and COPD, improving patient's coping skills and overall well-being.^{28,29}

Second, one patient suggested that we should routinely ask 'whether there was anything they wished to discuss

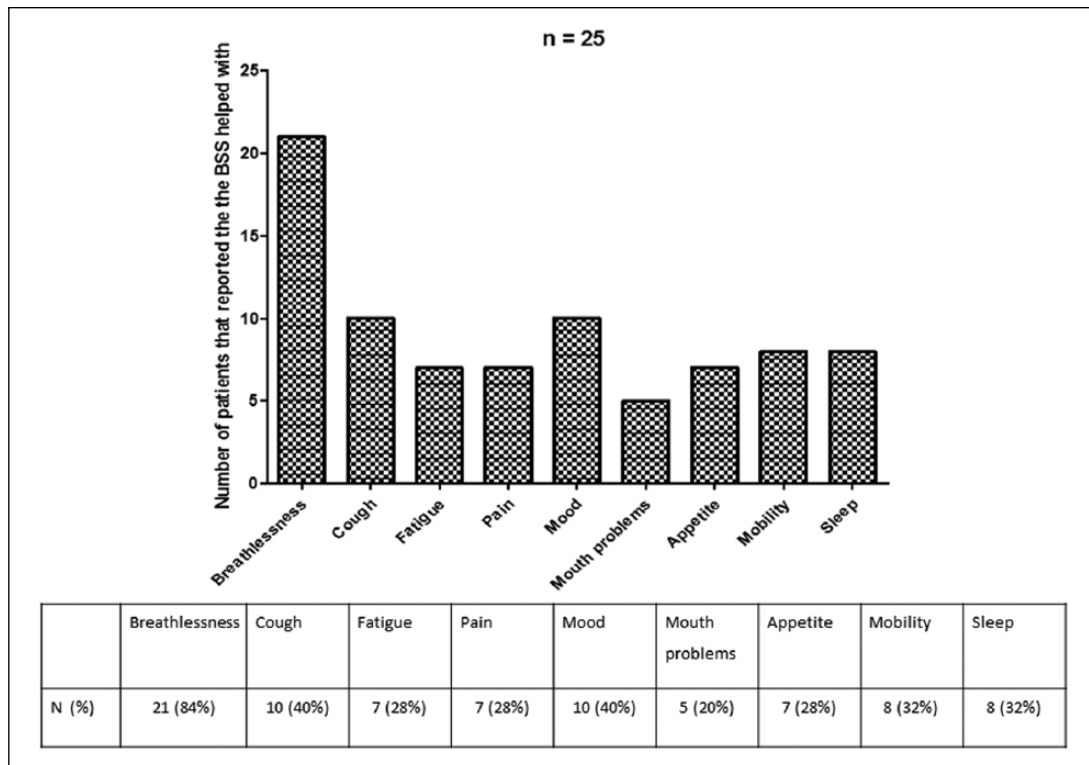


Figure 1. Did the breathlessness support service (BSS) help you with any of the following symptoms?

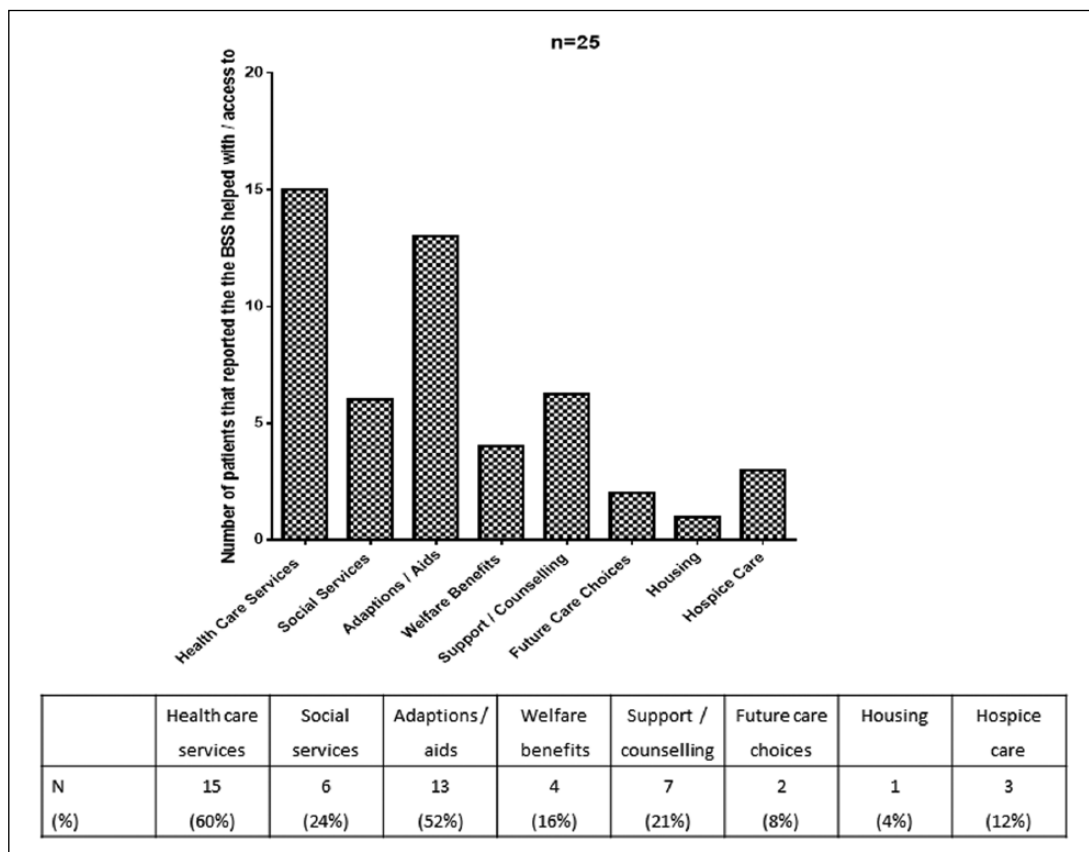


Figure 2. Additional help, support and information provision that patient reported they received as part of the BSS.

Table 3. Illustrative quotes about mechanisms by which the BSS improved individual patient's mastery over their breathlessness.**Theme 1: personalised care**

Patients appreciated the personalised care that they received in the BSS which was different from the previous experiences in the health-care system:

'I was able to discuss my personal feelings, that you don't talk to your family about so not to worry them'. (69-year-old woman with COPD)

'They gave very serious consideration to my condition. I felt supported'. (78-year-old man with ILD)

'Everyone at the clinic was very helpful and put me at ease'. (79-year-old woman with COPD)

'The BSS provided me with help and support, also they listened and you don't feel that your feelings are ignored'. (54-year-old woman with COPD)

'It makes you feel like you have a safety net'. (69-year-old woman with COPD)

Theme 2: caring nature of the BSS staff

Patients especially mentioned the caring nature of the staff which relates to the first theme:

'Everyone [BSS staff] was so helpful and kind'. (63-year-old man with cancer)

'Everyone that came to my home [physiotherapist/occupational therapist] were kind and put me at ease'. (79-year-old woman with COPD)

'It was nice to be able to discuss health issues with people who understand'. (60-year-old man with COPD)

Theme 3: importance of patient education and understand of their illness or symptom trajectory – patient empowerment

Patients felt empowered through the BSS and especially the educational component of the service:

'It helps you understand to control your breathlessness'. (78-year-old man with ILD)

'Supportive, instructive, helpful and practical advice provided'. (72-year-old man with COPD)

'How to manage my condition, understanding the progression of my illness'. (63-year-old man with COPD)

Theme 4: the effectiveness of context-specific breathlessness interventions – breathlessness mastery

The BSS provided patients support through specific breathlessness interventions which they could use themselves:

'They gave me coping strategies when I became breathlessness; also they gave me simple breathing exercises to help with my breathing'. (54-year-old woman with cancer)

'It was nice to be able to discuss health issues with people who understand; like things to make things easier for me, like housework, shopping. Simple things that meant a lot'. (54-year-old man with COPD)

'I felt more at ease discussing the state of my condition at home ... I was shown some good ideas (lifestyle modifications/pacing) for me to use in my home'. (56-year old man with cancer)

'It helped me to learn to relax, learn to breathe in a more controlled way'. (54-year-old man with COPD)

BSS: breathlessness support service; COPD: chronic obstructive pulmonary disease; ILD: interstitial lung disease.

during the consultation that they could not talk about with their family'. Reinforcing the importance of using open questions in the holistic assessment of these complex patients, encompassing patient and family autonomy and dignity which is the basic tenet of palliative care,^{30,31} this, by necessity, places value on the patient and their family's needs and desires regarding the patient's illness, treatment and likely prognosis. Our findings are consistent with previous authors who demonstrated that the adoption of the palliative care approach for all patients with advanced disease reduces levels of dissatisfaction with hospital-based services. It is argued that the adoption of the principles of palliative care in all aspects of health care would greatly improve satisfaction with health-care provision.³⁰

Research is possible despite the debilitating nature of the advanced disease in this group of patients as for those patients that responded to the questionnaire they reported that they viewed their involvement in research, as a beneficial and worthwhile experience, a finding consistent with previous studies.^{32,33} However, these findings must be interpreted in context of the low response rate. Moreover, these questions were regarding individuals' overall experience of research and not the experimental design of the BSS RCT. Acknowledging

these limitations, we feel that we have a duty to provide such patients with the opportunity to participate meaningfully in appropriate and relevant research for themselves and their families.

Limitations of the study

The low response rate and consequent small sample size of this study is a limitation of both this methodological approach and of this study. However, accepting this limitation, we feel that the patients who responded to the questionnaire are representative of the patients who received the BSS.

The aim of the questionnaire was to assess patient's experience of the BSS; it did not include specific question regarding severity and nature of symptoms, acceptability of specific interventions provided or length of appointments. The BSS in composition is complex and individualised to patient's individual circumstances; therefore, we built this questionnaire to measure the overall experience of the BSS and not its component parts.

We acknowledge that this study only provides information about the patient experience and satisfaction of accessing the BSS, but these data are important for service modelling and future development of breathlessness services.

Conclusion

Patients' satisfaction with the BSS was high, with many patients rating the care they received as excellent, reporting that attending the clinic was a worthwhile and a positive experience. In addition to providing changes in breathlessness support, the BSS acknowledged the complexity of breathlessness in the presence of coexisting symptoms, an approach that patients valued.

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Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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