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How does a new breathlessness support service affect patients?

To the Editor:

Breathlessness is a highly prevalent and distressing symptom in advanced disease but there is uncertainty about its treatment. Patients with breathlessness have complex needs, on average experience 13–14 other symptoms (such as pain, fatigue, sleep problems and depression) and frequently attend emergency hospital services [1]. As the best way of organising and delivering a service for the relief of breathlessness is not known, an interdisciplinary service was developed for patients with breathlessness in advanced disease and their carers: the Breathlessness Support Service (BSS) [2]. Here, we report the results of qualitative interviews of patients who received the BSS.

The BSS is distinct from previous services [3, 4] with respect to the incorporation of respiratory expertise, the widening of the range of professionals in the team and its primary mode of delivery in the outpatient clinic, with two appointments and a home visit within 4 weeks. At the first clinic visit, patients were assessed by respiratory medicine and palliative care clinicians and an individualised plan of treatment was agreed. They received a breathlessness pack with information, management and pacing guidance, a poem (to help breathing and relaxation during crises), a hand-held fan or water spray and an individualised crisis plan. A home assessment after 2–3 weeks was performed by a respiratory physiotherapist and/or occupational therapist, who developed a tailored programme based on the domestic situation of the patient. If needed, they referred the patient to rehabilitation or a social worker. After the second and final clinic visit, further individualised actions and a discharge plan were agreed. Summaries of both clinic visits were sent to the individual, with a copy to their general practitioner and referring staff [2, 5].

The BSS was evaluated by a randomised controlled trial (RCT) [5], according to the Medical Research Council Framework for complex interventions. The BSS significantly improved self-rated quality of life and the way patients managed their breathlessness, as assessed by breathlessness mastery. Patients recorded their mastery, and its effects on quality of life and function. Patients also had better survival, as a secondary outcome [6, 7]. The qualitative findings of the mixed-methods evaluation shed light on the components of the BSS, its mechanisms and how patients experienced the intervention.

The outpatient clinic of the BSS was based in the Cicely Saunders Institute at King's College Hospital in Southeast London, UK. 105 patients consented and were randomised for the trial [5]. Ethics approval was granted by the King's College Hospital Research Ethics Committee (reference 10/H0808/17). The study met the requirement of the local Research Governance Framework. All patients provided informed consent.

A researcher conducted interviews with a subsample of patients, 12 weeks after initially receiving the BSS. All interviews took place at the patients' homes, except one in a nursing home. The interviews were semi-structured and in-depth. A topic guide was used to ensure that all relevant topics were systematically covered (table 1). Interviews were tape-recorded and transcribed verbatim. Demographic data and clinical information were collected in the context of the RCT. Analysis was performed first by reading and coding the transcribed interviews. From the data, themes/categories were derived through an inductive approach.

These categories and their properties were constantly tested against newly emerging categories (constant comparison), thereby questioning and confirming them in the light of emerging findings and relating them to each other so that they became relevant on a more general level [8].

A total of 20 interviews were conducted. 10 patients had chronic obstructive pulmonary disease, six had interstitial lung disease (ILD) and four had cancer. 11 were men and nine were women, and the median age was 72 years (range 40–84 years).

TABLE 1 Qualitative study topic guide

Questions	Prompts
1. Using the service	
1.1. What did you expect from the Breathlessness Support Service?	Gain/benefit? In what way did you think they would help you? Cure/palliate?
1.2. What did you think they would do?	How would they help? Methods/means
1.3. Did they do what you expected?	
2. Location of care	
2.1. How did you feel about coming to the hospital for the service?	Waiting times; length of appointment; physical environment; location within the hospital (oncology); presence of partner
2.2. What was your journey to King's like?	Time; cost; reliance on others/hospital transport; parking/walking
2.3. How did you feel about being visited at home by the service?	Are the visits too long/too short? Presence of spouse/carer
2.4. You were visited at home and also you came to the breathlessness clinic at the hospital. Were you happy with this arrangement or do you think the service should be delivered all at home or at the hospital?	
3. Staff	
3.1. Whom did you meet at clinic?	Doctor/physiotherapist: do they know who they are?
3.2. Whom did you meet at home?	
3.3. How do you feel about the staff?	Doctor; physiotherapist; contradictory advice
4. Type of help	
4.1. What sort of help has the service given you?	Advice/information; psychological help; exercises; referral
4.2. Does the service provide the sort of information and care that you thought it would?	Is it what you expected when you were referred?
5. Frequency	
5.1. What do you think about the length of time between appointments?	Frequency; too long/ too short; source of help between appointments
5.2. How long do you think you would like to stay in contact with the service?	Short-term advice or long-term support
6. Information giving	
6.1. Was any of the advice or information they have given new to you?	
6.2. Have they given you too much new information?	
7. Outcome of service	
7.1. Has it improved your breathlessness?	
7.2. Has it improved any other symptom(s) or problem(s)?	
7.3. Has it improved your everyday life/quality of life?	What have you gained?
7.4. What did you find helpful about the service?	What do you like about it? Style/content
7.5. What did you find unhelpful about the service?	What don't you like about it? Style/content
7.6. What was the most useful thing the Breathlessness Support Service did or suggested in terms of managing your breathlessness?	
8. Improving the service	
8.1. How could the service be better?	What would a good breathlessness service be like? Timing, <i>i.e.</i> should referral have been earlier?
8.2. Would you recommend the breathlessness service (in its current form) to someone in a similar situation to yourself?	
8.3. Is there anything else you'd like to tell/ask me?	

The BSS included the provision of a hand-held fan, based on evidence of the effect of cool air on the face, which stimulates cold receptors situated in the upper airway [9, 10]. Patients said that they found the fan helpful: it was portable and fitted in a handbag and they carried it everywhere they went. It gave them a feeling of safety to have the fan at hand when they went out and if they started to feel breathless they could use it to help master their breathlessness. Severe episodes of breathlessness can escalate very quickly, often within seconds [11]. A treatment that provides a rapid response, such as the fan, may be valuable.

The physiotherapeutic support was included in the intervention as breathing training is a fundamental element of breathlessness management. The poem provided a strategy to support patients in managing an acute panic episode. The occupational advice and information pack were included based on evidence of the importance of providing education to patients and carers and of addressing issues that need adjustment in relation to daily activity and lifestyle [12]. Most of the participants found this support from the occupational therapist and physiotherapist helpful. They said it reinforced the positions they had learned and it made them more confident. They added the recommended adaptations to their routines and integrated the items into their home interior. For example, they stuck the poem on the fridge door or had the laminated sheet with breathing instructions at hand to remind them how to practise relaxation.

Yes the [...] breathlessness hasn't improved [...] but I deal with it better now than I did before so.

Interviewer: What do you mean "deal with it"?

[...] well, learning to relax and not get so stressed out, I mean I still get the old panic now and again when I've really put myself out [...], but most of the time I deal with it quite easily. [...] That poem has helped me the most, because it's something that I can [...] do anywhere. If I'm sitting on the train I can do it and [...] that's been the biggest help definitely.

... giving you tips on how to do things [physiotherapist and occupational therapist visit], you know sort of little things like when you're using the vacuum cleaner, to breathe out when you push it out. Little things like that, you don't think of. Um, there were quite a few things and they're logged in the memory bank, but I remember them as I do them it's become automatic now.

Patient with cancer

Concerning the format of the intervention, patients expressed preferences regarding the place, timing and approach of the intervention. Most patients (n=16) were happy to come to the BSS. Nine people had a preference for a clinic visit. Due to the disability caused by breathlessness, they rarely went out, didn't socialise and a clinic was an excuse to speak with someone. Related to this need for social contact was the suggestion to organise group sessions. Patients suggested ideally regular and ongoing contact with the service. The welcoming and person-centred approach of the service was very much appreciated.

... They both stood up, shook your hand and said "Hello nice to meet you", you know? [...] How many doctors do you know that [...], say "Take a seat" [...] People don't even look at you...

Patient with cancer

Patients valued the integrated approach of the BSS. They said it was a new experience for them that their breathing problems were treated holistically, with attention to other symptoms and physical health.

I was a bit surprised that they went outside the particular problem [...] They talked about my general health and that sort of thing... I suppose it's interconnected. You can't have it in isolation.

Patient with ILD

These findings provide important evidence regarding how the specialist service was received by patients. This enhanced our understanding beyond the specific items and knowledge, to the mechanisms and the format of the BSS. It was the integrated approach and expertise of palliative care, respiratory medicine, occupational therapy and physiotherapy that was beneficial and that provided patients with a sense of mastery that improved their quality of life. This was achieved through a person-centred approach, directed at patients' specific concerns and tailored to the particular environments in which patients and carers experience this complex symptom.



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New breathlessness support service helps patients with person-centred, individualised care, boosting confidence <http://ow.ly/RMIYo>

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