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The impact of a breathlessness intervention service (BIS) on the lives of patients with intractable dyspnea: A qualitative phase 1 study

SARA BOOTH, M.B.B.S. FFARCSI F.R.C.P.,[1] MORAG FARQUHAR, PH.D., M.SC., B.SC., R.G.N.,[2]
MARJOLEIN GYSELS, B.A., M.A., PH.D.,[2] CLAUDIA BAUSEWEIN, M.D., M.SC.,[2]
AND IRENE J. HIGGINSON, B.MED.SCI., B.M.B.S., F.F.PH.M., PH.D., F.R.C.P.[2]
[1]Addenbrooke's Hospital, Hills Road, Cambridge, UK
[2]Department of Palliative Care, Policy & Rehabilitation, King's College, London, UK

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ABSTRACT

Objective: Disabling breathlessness is the most common symptom of advanced cardiopulmonary disease. It is usually intractable, even when patients receive maximal medical therapy for their underlying condition. A pilot study was undertaken to evaluate a newly formed palliative Breathlessness Intervention Service (BIS).

Methods: The methodology followed the Medical Research Council's Framework for the Evaluation of Complex Interventions (Phase I). Qualitative interviews were completed with patients and relatives who had used the service and clinicians who had referred to it. The focus of the interviews was the participants' experience of using BIS.

Results: Patients valued the positive educational approach taken to breathlessness, emphasizing what was possible rather than what had been lost. Non-pharmacological strategies, especially the hand-held fan and exercises, were rated very helpful and new to patients. Participants reiterated that breathlessness was frightening and isolating, exacerbating the disability it caused: the easy access to advice and flexibility of BIS helped to alleviate this. Participants wanted a written record of the advice given. Carers welcomed the focus on their needs. Clinicians valued sharing the management of patients with an intractable problem.

Significance of results: This Phase I study has helped to remodel the service rapidly by uncovering the aspects of BIS that users find most valuable and areas that need change or improvement. The BIS needs to provide written information, to reinforce and extend contacts with other agencies to build on support it already provides for patients and carers, and extend its flexibility and accessibility. Providing a "drop-in" service and continuing education after the initial program of contacts is completed could be a useful service development, warranting further evaluation. A qualitative methodology involving service users and referrers can help to shape service development rapidly.

KEYWORDS: Breathlessness service, Intractable breathlessness, Qualitative evaluation, Palliative, Rehabilitation approach

INTRODUCTION

Breathlessness is the most common and distressing symptom of both malignant and non-malignant advanced cardiorespiratory disease (Edmonds et al., 2001). Once treatments aimed at reversing the underlying disease become ineffectual, the symptom itself is very difficult to palliate and significantly reduces quality of life not only for the patient, but also for family members and other carers (Booth et al., 2003). Palliative care services have historically been developed to meet the needs of terminally ill cancer patients, however nonmalignant

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Corresponding author: Dr. Sara Booth, MBBS FFARCSI FRCP, Macmillan Consultant in Palliative Medicine, Box 193, Addenbrooke's Hospital, Hills Road, Cambridge CB2 2QQ, UK. E-mail: sara.booth@addenbrookes.nhs.uk

chronic disease follows a different pattern: patterns of breathlessness in cancer and non-malignant disease are distinct, and patients and carers with different types of illness may have different needs for services. Once patients with cancer become intractably breathless they usually have a relatively short time to live, becoming breathless at rest over a shorter period of time. Patients who develop breathlessness as part of chronic obstructive pulmonary disease (COPD) usually live with gradually worsening symptoms and increasingly devastating consequences for many years. The effects on the patient and family with malignant or non-malignant disease include increased social isolation, reduced levels of activity, chronic anxiety, low mood, loss of employment, and other unwanted changes in patients' and carers' usual roles and perceived status.

The fact that patients with COPD, heart failure, and other non-malignant diseases accompanied by breathlessness have palliative care needs has only recently been widely recognized (Bredin et al., 1999; Edmonds et al., 2001). Most palliative care intervention studies to date have been carried out in patients with cancer and have been set up as breathlessness clinics where patients attend for a set number of consultations at a cancer center or hospice (Corner et al., 1996, Bredin et al., 1999; Hately et al., 2003). Many experience attrition, as breathless cancer patients often deteriorate rapidly and are not able to get to the hospital. The Breathlessness Intervention Service (BIS) was set up in 2003 to be flexible, responding to patients' wishes to be seen where it was most convenient for them and to serve the very disabled from any diagnostic group (i.e., malignant and non-malignant). There was no provision to give either emergency or long-term care directly to patients but to work with primary care and other specialists by giving advice to patients, carers, and professionals that focused on palliating the symptom of breathlessness and the problems it caused. Each intervention used in the service was based on literature reviewed in the preclinical phase of the Medical Research Council's (MRC) Framework for the Evaluation of Complex Interventions (Medical Research Council, 2000). For example, evidence of the efficacy of a hand-held fan comes from Schwartzstein et al. (1987); efficacy of exercise, rehabilitation, and education are well documented in cardiopulmonary rehabilitation (although the efficacy of individual components of the programs are more difficult to evaluate); and evidence for psychological support for the patient comes from Bredin's work with cancer patients (Bredin et al., 1999). BIS included a research component from the outset so that it could be remodeled continually to meet the needs of patients and families most effectively. This article reports on Phase I of this.

The BIS had been operating for about 8 months when Phase I was undertaken. The service was introduced initially in one primary care trust (PCT) through contacts with general practitioners (GPs) particularly interested in palliative care and its work spread by word of mouth and by presentations to local meetings. The BIS clinicians running the service were receiving anecdotal feedback from patients and GPs during this early period and had started to refine and simplify referral guidelines (e.g., putting them on the hospital website and using the same "downloadable" pro forma for telephone/fax referrals). Within the hospital, contacts were made particularly with the Respiratory Medicine Department (including the Acute Respiratory Team, ART, of nurse specialists), which also referred directly to the service.

The BIS is staffed by a specialist physiotherapist (P.F., 3 days a week) and a Macmillan consultant in palliative medicine (S.B.). Secretarial support is provided from within the palliative care service.

METHODS

Local Ethics Committee approval was granted for this project.

Setting

Eligible participants were adult patients with intractable breathlessness (receiving maximal medical therapeutic treatment) living within the catchment area of Addenbrooke's National Health Service Trust. This is a tertiary referral and cancer center: the hospital palliative care service for inpatients receives approximately 1000 referrals a year—about 85% having malignant disease. Other inclusion criteria were fluency in spoken English and absence of cognitive impairment in order for participants to take part in the interviews.

Qualitative Interviews

All patients ($n = 10$) and carers who had used the service since its inception were invited to participate in a pilot evaluation of the service. Patients were approached in writing and M.F., a research associate independent of the service, then telephoned participants to arrange home visits for consenting and interviews. Patients and carers were interviewed separately where possible, and all interviews were tape-recorded and subsequently transcribed by a transcription service.

The interviews were unstructured but followed a topic guide developed by M.F. based on a review of the literature and discussions with BIS clinicians. Questions centered on participants' experience of the service, not on their experience of being breathless, which had been previously investigated in the preclinical phase (Booth et al., 2003). GPs and the ART nurses who had referred patients to the service were also invited to participate in a similar way; their interviews focused on their experience of referring patients to the service.

The BIS service model is described in Appendix 1.

Analysis

The transcripts were checked and read independently by M.F./S.B. to gain familiarity with the data: analysis commenced with line-by-line open coding. The process of constant comparative analysis was applied, taking information from the data and comparing it to emerging categories. Sections of the text from the transcribed interviews relating to particular topics or themes were labeled and related to each other, giving rise to more abstract generalizations. NUD*IST software was used to facilitate this process.

RESULTS

All 10 patients and carers agreed to be interviewed: one carer was then unable to participate due to his wife's sudden death. One patient and carer were interviewed together at the patient's request and one carer was interviewed by telephone due to their geographical location.

Five patients had COPD, two had cancer (colon, myelofibrosis), two had interstitial lung disease, and one had heart failure. Six were female and nine were married and living with spouses. Carers were not always spouses; for example, within one family the adult daughter was the carer to her father (BIS patient) and mother. One widow was living in the annex of her daughter's house. Five GPs were approached to take part in the study and all agreed, although it proved impossible to arrange an interview for one GP; this represents an unusually high GP response rate.

Interview data from participants are presented in Appendixes 2, 3, and 4, grouped by the three main themes that were common to patients, carers, and referrers. Other themes are listed in the text. Related patients (P) and carers (C) have the same identity number. General practitioners' comments (GPs) and respiratory nurses (R) are assigned individual identity numbers.

Following are the main themes identified.

Theme 1: Psychological Support Gained by Recognition of a Frightening, Little Known, and Poorly Understood Symptom (Appendix 2)

Patients and families remarked how little they knew about breathlessness before they experienced it, and for them the recognition of breathlessness as needing management in its own right was helpful, reinforced by the practical help received from BIS. All participants noted that breathlessness is not recognized or talked about commonly in the wider community.

Being listened to and empathized with were valuable in themselves, and patients and carers frequently expressed a need for someone to call on when they felt frightened. Patients and carers also found the strategies taught by the service supportive as they could be used to take some control over the condition, for example, looking at what was possible rather than dwelling on what had been lost and a tool to reduce anxiety. The easy access, in normal working hours, to BIS for advice was greatly valued. Telephone advice was repeatedly mentioned as a useful resource, particularly as many of the patients lived in rural areas, as was the flexibility of home or out-patient consultations. Many said that having some written record of their personal "breathlessness control regimens" would be a useful reinforcement that would be especially useful when telephone advice was not available. No out-of-hours advice was requested during the period of the study.

The referrers all gave encouraging feedback about the BIS from their patients (R2: "They have all been very positive about outcomes"), which echoed comments from patient/carer interviews. For referrers the aspects of the service particularly valued were the focus on symptom relief and the time given to consider it: (GP7: ". . . to tell their story and make sense of it and giving some techniques to do within their lifestyle changes.") The referrers were pleased to have access to a service that complemented their own. The ART nurses, for example, saw a distinction between their role and that of palliative care, for instance, the BIS service would lead on "opening up" a discussion of end-of-life issues.

For all referrers, chronic intractable breathlessness was a difficult problem that was distressing for patients and relatives whom they were seeing regularly for a considerable period of time and wanted to help. Some described feeling powerless to help breathlessness and were also pleased to have another opinion to ensure they were doing everything they could for the patient.

All the GPs had witnessed significant fear and anxiety in carers and patients alike. All felt that chronic breathlessness was a "hidden" problem of greater magnitude than suggested by health statistics (GP 10: "a huge problem there") because, once dyspnea became irreversible it was largely managed in general practice. The GPs reported being happy to act on advice given by BIS and keen on intermittent, regular review of patients with difficult problems.

Theme 2: The Educational Role of BIS Was Valued (Appendix 3)

The education provided by BIS was considered central to its effectiveness. Carers learned what they could do to help those with breathlessness, patients found having some understanding of the symptom helpful in itself, and referrers found the education accompanying the interventions useful for both the individual patient and for their management of other patients.

The day-to-day clinical contact with BIS was educational in itself for referring clinicians. GPs valued the advisory role of BIS, in close touch with the primary health care team; for example, all valued phone calls after key appointments (to exchange large volumes of information rapidly) and would welcome any rapid communication, for example, faxes. All valued the summaries produced by the physiotherapist at the conclusion of a period of intervention outlining the recommendations to the patient. One of the GPs reported that a joint visit "actually educated me in breathlessness" (GP7), but there was a recognition that joint consultations were not always possible.

GPs favored education sessions for the whole practice, as primary care teams have often received little training on managing breathlessness.

Theme 3: Expert Symptom Management Was an Important Aspect of the BIS (Appendix 4)

This theme was expressed in different ways by patients, carers, and clinicians. The patients and carers were particularly keen on some of the nonpharmacological self-management strategies taught by P.F. and that they were "listened to" about their breathlessness. Time and again there were comments on the usefulness of the hand-held fan from all participants.

Psychosocial interventions were also seen as central to good symptom control. Interest in both the patients' and families' problems, the discussion of end-of-life issues, and the revitalizing nature of a focus on active self-management strategies were commented on.

The attention to carers' needs for psychosocial support and education in their own right was considered extremely important by all participants.

As there are few teams that manage a symptom particularly in the community, a written introduction to BIS would have helped reinforce the central role of education in the way that it functioned (which is different from most clinical teams). It would also allay potential concerns (expressed by one or two participants) about BIS being based in oncology and associated with Macmillan. It would also clarify the extent and limitations of the team's involvement with patients who have many comorbidities and see many other clinical teams.

DISCUSSION

BIS has already acted on the invaluable insights provided by patients, families, and clinicians during the course of this Phase I study, which had exceptionally high response rates from all participants. The study confirmed some feedback that BIS clinicians were hearing from patients directly, but also provided much that was unknown. It elucidated the interventions that need testing in the next phase (Phase II) of the evaluation of this complex intervention, that is, education, psychosocial support, and the efficacy of expert knowledge in symptom control.

Clinicians, families, and patients all felt isolated in dealing with breathlessness: less attention is paid to breathlessness than pain, although it is almost as common, and there are fewer consistently helpful interventions known or resources available and less public understanding of it (Theme 1). The support of BIS was welcomed as helpful in itself, but a planned Phase II study would be needed to quantify this clinical effect. The efficacy of psychosocial support in medical symptom control has historically not been quantified in studies: being "kindly" has been considered intrinsic to the work of clinical teams and helpful only as a secondary effect of this. It is only in recent years that there has been a greater understanding of how psychosocial interventions can change the pharmacology of the central nervous system and therefore psychological status (Baylis et al., 2005). However it is increasingly recognized that psychosocial interventions may be efficacious in chronic conditions (Lemstra & Olszynski, 2005) and therefore fundamental to management strategies for intractable, distressing symptoms. Formal assessment of the impact of psychosocial interventions is planned for Phase II, as the education and support given by BIS was continually and widely cited as important by participants. As BIS interventions take time and are added to normal best care and delivered by specialists, this incurs costs that would need to be justified by results.

Learning more about how to improve breathlessness (and to increase their understanding of it; Theme 2) was reported by participants to increase quality of life both by giving them some control over the symptom and reducing attendant anxiety. Increasing self-efficacy of patients with chronic illness is associated with a reduction in depression and an increase in quality of life (Bisschop et al., 2004; Barlow et al., 2005).

The needs of carers looking after the chronically ill patient have not been widely recognized until recently (Booth et al., 2003, Harding & Higginson, 2003): all were appreciative of the education given and interest shown in their needs, and this will continue (Theme 3). It is hoped this may translate into a greater longevity in caring with a lower incidence of anxiety and depression. Thus the effect of "caring for carers" and reducing carer distress will be a component of the Phase II evaluation. Giving the same education to carers reduced their anxiety by increasing their sense of control over a potentially terrifying situation that reduced "distress due to breathlessness" within the family. The helplessness and anxiety generated by watching a breathless person without knowing how to help is well documented (Booth et al., 2003).

GPs and the ART nurses themselves found it helpful to learn some interventions that could help breathlessness (Theme 2), which could be used for patients not referred to the service and taught to other clinicians in their teams. Once clinicians feel able to help breathlessness it may be elicited more frequently: it has been shown previously (Roberts et al., 1993), and was highlighted again here, that many clinicians do not ask about breathlessness as they do not feel they can do anything to help.

All were surprised how helpful they found the non-pharmacological strategies (Theme 3), particularly the fan and the exercise program. Further evaluation is necessary in order to quantify the improvement produced by these techniques in different diagnostic groups, but the testimonies given directly to clinicians and to the researcher are striking.

BIS is now offering more information before visiting for the first time (Theme 3), to explain how the service works and what sort of help it can give (e.g., the importance of exercise as a health intervention with a possible efficacy comparable to that of drug therapy) and to be used in combination with it and giving greater emphasis to the fact that BIS is part of oncology for managerial, not diagnostic, reasons.

The BIS is considering developing local drop-in consultations some months after the "final" routine consultation for patients and is making stronger connections with other providers of rehabilitation and education (e.g., hospice services, cardiopulmonary rehabilitation programs) in order to provide these at different stages of illness. BIS is also trying out different ways of recording and communicating the self-management strategies developed with patients and carers (Theme 2), for example, accessible aide-memoires of the specific manoeuvres helpful for that individual when he or she is breathless and that help to keep the symptom at bay (Theme 3).

CONCLUSIONS

A flexible BIS that works with patients and carers where they are, and in close liaison with the referrers and other clinicians caring for them, is valued by all these users and appears to perform a distinct role. Continuing to foster and develop links with other specialist services (exchanging information and skills) would seem an effective way of providing this service more widely and enabling it to be "tailor made" for an individual's needs. A service like BIS, which operates outside the expected norms of hospital specialist services, needs to be carefully introduced to patients and carers in order to be as effective as possible as rapidly as possible.

Many non-pharmacological strategies are still unfamiliar to others working with breathless patients and BIS can make them more widely known. Education itself, in the broadest sense, can have an effect on improving breathlessness, and this needs to be provided in many different, easily accessible forms for patients and carers in addition to formal seminars and other conventional teaching at present available to clinicians. Follow-up clinics that can be accessed when patients or carers choose to are worth piloting and evaluating. Written or recorded reminders of what has helped patients and families are valuable ways of reinforcing the education given to patients and carers, and carer involvement seems to be crucial to success. Further evidence of the difficulties with which carers live is provided in this study and also their desire for help targeted at their needs. The multiplicity of services with which the chronically ill patient may have contact is underlined again and so is the potential confusion this may cause patients and carers, particularly as all are keen to audit the service they provide. Participants are pleased when liaison between services takes place and the volume of information they receive is reduced. Methods of doing this within a large organization need to be designed and considered.

Patients and carers often value being asked to take part in palliative care research and make great efforts to participate—the data provided should be used as widely as possible to improve patient care, and using it in the education of clinicians may be one way of doing this. This will be evaluated in a later study. The effects of education and the support it gives needs quantifying to judge whether it provides sufficient "added value" for the cost involved and to learn which are the most effective strategies to help patients, carers, and clinicians manage this difficult and distressing symptom.

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APPENDIX 1: BIS SERVICE MODEL

Consultation 1: Day 1. A full history was taken (S.B. and physiotherapist) with quantitative assessment of quality of life (McGill questionnaire) and severity of dyspnea using a variety of tools—usually that developed at the Royal Marsden (Cohen et al., 1995). Patients were asked to set out three goals that they wanted BIS to help them achieve. Carers were assessed (separately or with the patient) to identify their needs.

Consultation 2: About Day 8. Patients seen by physiotherapist, who carried out repeatable individualized exercise tolerance tests and designed a tailor-made exercise program. Patients and carers were given advice and education about using a handheld fan, breathing exercises, optimum positioning, activity pacing, and help with practical issues related to the activities of daily living. Referral was made to other specialist services, for example, cardiopulmonary rehabilitation. Close contact was maintained with the primary care team and other involved clinicians (e.g., respiratory nurses).

Consultation 3/phone call: Around Day 22–29. Physiotherapist checked progress and answered any questions.

Consultation 4: Final routine assessment (during weeks 4–6 after Consultation 1). Any improvements noted, useful strategies identified and encouraged for longer term use.

This pattern was modified if patients were being seen simultaneously by another service, for example, hospice day center. BIS clinicians set out to monitor and minimize the number of agencies involved in patients' care at any one time, particularly where there could be service overlap.

APPENDIX 2: INTERVIEW DATA FROM PARTICIPANTS ON THEME 1

Theme 1: Psychological support gained by recognition of a frightening, little known, and poorly understood symptom.

C10: "I didn't know anything about it. . . . It's a strange situation . . . never really associated it with people just trying to do normal run of the mill things."

PO6 (and carer present): "There's quite a lot of people and I mean they've . . . done nothing (and they are breathless). . . .

And it's awful if you're trying to catch your breath and that. Mine's on exertion. It is (very frightening)."

C10: ". . . to see someone breathless is quite frightening and distressing."

GP4: "I think that anything that anyone can come up with is always helpful really. . . . With regards to this . . . particular patient I referred was 'any help would be good.' . . . It's extremely good to have anyone else's viewpoint in these situations."

GP4: "I think it is distressing and difficult. I find it very distressing when you come to see someone who is breathless. . . . You don't get the immediate relief like you do with pain relief."

GP10: "I mean it's actually quite a difficult situation to cope with. I mean clearly you feel empathy with the patient who is breathless. . . . It must be an awful situation to be in. . . . It's probably a little less quantifiable than pain; in a way you've actually got an objective to treat and by and large, got the sort of means to do that with your sort of drugs and things. Whereas breathlessness . . . very often you feel a little bit less empowered to deal with that."

R2: "The nice thing for us is that there is another port of call where somebody was going to be interested in these patients when . . . it almost seemed as though other people were saying 'well that's it, you've got to . . . This is it mate.'"

R1: "I would like to see what goes on . . . that would give me an opportunity to speak with authority when we have to tell the patient what it is all about. . . . But regular appointments would be, like, duplicating and I think they spent a lot of time with these patients, . . . certainly more than we could possibly have to find as extra time to go to sit in clinics."

R1: "We get a lot of information back, . . . a good quality report."

R1: ". . . from the patient's point of view, they . . . appreciate . . . intensive interest in them . . . when they've got to the point where there seems to be very little else, . . . but it does seem to help them."

R2: ". . . it's the coping side of life. If they are not coping at home, if they are getting into panic situations, if their breathlessness is dire to them . . . even before it is getting dire . . . then I would refer to (BIS)."

APPENDIX 3: INTERVIEW DATA FROM PARTICIPANTS ON THEME 2

Theme 2: The educational role of BIS was valued.

P04: "I was thrilled to bits to be able to be getting some knowledge of what my complaint was all about . . . that they're doing something about it."

C10: ". . . it has helped her, which is the important thing. . . . My wife's been, not necessarily sorted, but understanding what she can and can't do better . . . takes that sort of stress and worry away from us."

C10: "As a family it has, because we all now understand better what the problem that she's had. So we can adapt our lives, our way of living more so around my wife to compensate . . . to help her."

C10: ". . . get her to do . . . the things that she's been told to do . . . make sure that she's doing the plan that they've set out for her."

GP4: "I think coming to talk to us as a whole and educating us generally . . . would be useful."

GP7: "I think getting a fan without the education, without the one-to-one education as to why they are using it and what the intention is, they don't necessarily take on board . . . people are sort of suspicious of the simplicity of it. . . . I've spoken to patients and . . . they've said 'oh they gave me this fan, but it works!'"

R2: "It's education aspect of management of breathlessness is what we are providing, and it is very, very difficult to get that across well. . . . [Having people] who're really expert in the management of that is incredibly helpful for us."

R1: "It will add a palliative aspect of, well, . . . reinforcing what we have said."

APPENDIX 4: INTERVIEW DATA FROM PARTICIPANTS ON THEME 3

Theme 3: Expert symptom management was an important aspect of the BIS.

The Efficacy of Hand-Held Fans

CO5: ". . . tiny but so effective! . . . brilliant . . . definitely . . . it does seem to work."

PO5: "The fan has certainly made a difference . . . especially . . . [at] night time; if I do go to bed and use them it soon quietens down."

PO6: "It's something I can pick up straight away. . . . I take it out with me."

The Usefulness of Supervised Breathing Exercises

PO6: "Well, she's shown me how to breathe and . . . to walk on the spot and . . . do their exercises. . . . [The fan] is very good, . . . an instant thing."

PO8: "Now they have taught me to breathe from my stomach . . . instead of up here and the oramorph has helped that. . . . They are a great help, especially learning to breathe from here and breathing in and out."

GP7: "I was very impressed by the simplicity of the exercises."

Psychosocial Support

R1: ". . . ongoing pulmonary rehab . . . because they do this six weeks intervention. . . . They are back in a group of like-minded people. They really, really enjoy it, . . . socially involved again where they have been socially isolated, . . . tip–top condition and perky and psychologically much improved as well, . . . and then "whish" . . . finish. . . . Refresher pulmonary rehab would be good."

Discussing End-Of-Life Issues

R1: "Unfortunately the lady seemed to be waiting to die; she had been given a diagnosis of end stage lung disease and was given 2 years to live (2 years ago) . . . she had got to that point and gets very anxious about the slightest little thing. . . . She went to the BIS and . . . has done wonders . . . since the oramorph. . . . She is a very different woman. . . . I think she has faced a lot of issues. . . . Dealing with the stuff you can't talk about."