Clinicians and researchers develop approach to shortness of breath

August 18 2015

We all feel breathless from time to time: we've run for the bus, we've climbed a steep hill, we've cycled quickly to a meeting we're late for. For some people, however, even the smallest of exertions – walking to the bathroom, getting dressed, even talking – can bring on a shortness of breath.

Daily, long term breathlessness is almost certainly a sign of an

underlying, and often serious and advanced, condition such as chronic obstructive pulmonary disease (COPD), which causes inflammation of the lungs. It can also occur in some advanced cancers. Both are conditions that cannot be cured, only managed.

"There's been lots of research done into symptoms of advanced disease such as pain and there are good treatments – both pharmacological and non-pharmacological – but it's a different situation with breathlessness," says Dr Morag Farquhar from the Department of Public Health and Primary Care at the University of Cambridge.

For several years now Farquhar has been involved with the Breathlessness Intervention Service (BIS), set up by Dr Sara Booth at Addenbrooke's Hospital in Cambridge who, importantly, saw the need to formally evaluate the service.

Unusually for an outpatient service, the service is often delivered in patients' homes. "A lot of these people are too breathless to leave the house," explains Farquhar. There is another, important reason why it is beneficial to visit patients in their own home, and that is to see the patient in their own environment, so that the intervention – advice and treatment – can be tailored specifically to their circumstances.

"BIS is what's known as a 'complex intervention', one that has a number of different components, often delivered by a number of different healthcare professionals," says Farquhar, who has been involved in developing and evaluating the service in collaboration with Booth, with funding from the National Institute of Health Research, Macmillan Cancer Support and the Gatsby Foundation.

BIS is not aimed at everyone who is living with breathlessness, she explains, but rather at those who are struggling with the condition – and this applies both to patients and their carers. "Breathlessness can be very

frightening for family members who are caring for their loved one. They often struggle to know what to do. They will do things like keeping asking how they can help, and of course the patient can't respond as they can't speak. Or they'll take the approach where they won't let the patient do anything because they're worried it's going to make them breathless – but this is counterproductive, as the patient will get muscle wasting and weakness and so will get breathless more easily."

The intervention is multidisciplinary: patients have access to palliative care consultants, specialist occupational therapists and physiotherapists, and psychologists if needed. It involves both pharmacological approaches – such as medicines, oxygen and anti-anxiety medication – and non-pharmacological strategies. These include teaching the patient how to break the cycle of anxiety, using meditation and relaxation techniques.

Patients are also taught how to plan and pace themselves – where previously a trip to the supermarket might have seemed overwhelming, if they can learn how to plan their trip, think about how they can break it into small, manageable steps that allow them to keep breathing steadily, then it can once again become achievable.

Small, hand-held fans can also help a patient recover their breath, and it was here that Farquhar and Booth's evaluation threw up something surprising: when they asked patients and carers about the fans, they said it was as much about how the fans were presented to them. By "delivering" the fans, rather than just "giving" them, as Farquhar puts it, the patients had greater success.

"[The BIS clinicians] didn't just give the patients the fans and say 'Here, use this', because the patients would've just thought 'Well, that's not going to work'. It was the fact that they showed them how to sit, how to use it, explained how it worked – this gave it credibility."

The BIS team have had interest from a number of other hospital trusts around the UK, some of whom now have services modelled on BIS, but there has yet to be a nationwide adoption of the service. It is across the Atlantic in Canada, however, that BIS has arguably had the greatest impact.

In 2006, Farquhar and Booth met Professor Graeme Rocker, from the Department of Medicine at Dalhousie University, Halifax, Nova Scotia, during a meeting in London. He was already "moving in the direction of more community-based care", he says, but was impressed by the work of the BIS collaboration. He was particularly inspired by their emphasis on listening to patients and getting a better sense of their symptoms that was independent on any particular diagnosis. "I already had some ideas how I should run the service but could see that the Cambridge team was much more clued in to effective evaluation of complex interventions."

Rocker went on to develop the appropriately-named INSPIRED (Implementing a Novel and Supportive Program of Individualized care for patients and families living with REspiratory Disease) and adapted Farquhar and Booth's approach to evaluating its success.

And the statistics show just how effective INSPIRED has indeed been. Its outreach programme for tackling breathlessness in COPD led to a 60% drop in visits by patients to emergency rooms and for hospital admissions. INSPIRED is now being emulated by 19 teams across the 10 Canadian provinces.

Rocker is grateful to the Cambridge team. "I would not have been successful with INSPIRED had I not learned from BIS, and particularly from Morag, the importance of evaluation. It's invaluable for proving to hospital administrators that you have a programme that works."

In 2014, Farquhar, Booth and colleagues published the results of a

randomised controlled trial which found that BIS was more effective – and cost-effective – for treating patients with advanced cancer than standard care. Almost all the participants reported a positive impact, with reduced fear and worry, and increased confidence in managing their breathlessness.

It was the accumulation of tips and strategies, which build up into something bigger, that patients and carers told Farquhar made the intervention so helpful. Patients and carers recognise that the condition isn't going to go away, but they now have a new way of living with their breathlessness.

"One of the most powerful things they talk about is how the service teaches them that breathlessness won't kill them. People are frightened that the next episode of breathlessness might finish them. They find it liberating to be told by a professional that it won't."

More information: "Is a specialist breathlessness service more effective and cost-effective for patients with advanced cancer and their carers than standard care? Findings of a mixed-method randomised controlled trial." *BMC Medicine* 2014, 12:194 DOI: 10.1186/s12916-014-0194-2

Provided by University of Cambridge