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It's hard to talk about breathlessness: a unique insight from respiratory trainees

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ABSTRACT

This paper describes how difficult it can be to discuss the experience of breathlessness with patients, as identified by respiratory trainees in a psychology-led workshop. The reasons why it is considered an essential role for clinicians to facilitate conversations about patients' breathlessness are outlined within the context of the challenges of respiratory care. The benefits for both patient and clinician are described including rapport building, more focused and targeted consultations, and increasing a patient's receptivity to interventions. The value of preparing a patient to actively engage with their breathlessness management is highlighted. As a way to support clinicians to initiate talk about breathlessness, a 'five-step guide to talking' is presented.

KEYWORDS: Behaviour change, self-management, motivational interviewing, frightening breathlessness

Introduction

Breathlessness is a widely experienced symptom of chronic respiratory disease. It is a frequent cause of presentation to acute services, with chronic obstructive pulmonary disease (COPD) the second most common diagnosis leading to emergency hospital admission in the UK.[1] Breathlessness is often the symptom that leads to patients with COPD presenting acutely to hospital. Despite this high burden on health services, breathlessness in respiratory disease is undertreated and the impact on the patient is often overlooked.[2,3] This paper seeks to describe how respiratory clinicians can work more effectively with their patients to address the challenges of breathlessness using communication and collaborative working. The barriers to talking with patients about their experience of living with breathlessness are identified through the honest accounts of a group of respiratory trainees. In an attempt to build a clinician's skills and confidence in facilitating and prioritising these conversations, this paper concludes with a 'five-step guide to talking'. The recommendations identified could be useful to all clinicians caring for patients who present with breathlessness, not just respiratory clinicians, as many patients are under the care of non-respiratory clinicians in the acute setting.

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The burden of breathlessness in chronic respiratory disease

For the individual who lives with a chronic lung condition, the impact of their breathlessness is wide ranging. Lifestyle is often detrimentally affected with reduced physical activity and disrupted social relationships. In addition, emotional wellbeing and personal identity can be profoundly influenced. Poor perceptions of the future and a feeling of hopelessness are commonly reported.[4] As a person's condition progresses, the impact of breathlessness can be increasingly disruptive, disabling and frightening, leading to significant levels of depression and anxiety.[4] Fear and anxiety can drive further breathlessness through the fight-flight response, with symptoms of hyperventilation and panic attacks, causing a vicious cycle of distress.[5] An often overlooked factor is the distress which breathlessness brings to those caring for the patient, a factor that can often drive presentation to the acute services.[3]

Approaches to managing chronic breathlessness

There is no cure or 'quick fix' for progressive lung disease. The clinician's key task is to make the correct diagnosis and treat the underlying condition. Appropriate therapy may include intervention for tobacco dependence, inhaled and nebulised medication for airway obstruction, opiates, non-invasive ventilation and long-term oxygen therapy for those with respiratory failure (not as a treatment for breathlessness). Despite these interventions, breathlessness can remain severe for many people, for much of the time. This often poses a challenge to clinicians when dealing with worsening breathlessness, despite medically optimised disease. The literature identifies other clinician-based factors impacting the management of breathlessness, including a lack of confidence in prescribing,[2,6] poor understanding of the patients' experience,[7] under-referral to pulmonary rehabilitation (eg due to lack of knowledge about how, why or where to refer)[8] and limited access to dedicated psychological therapy within the wider respiratory multidisciplinary team.[9]

In addition, it is recognised that patients themselves play an essential role in the reduction of their suffering and corresponding impact.[10] An individual who can embrace their role in breathlessness management, using a range of non-

pharmacological strategies (eg pacing, breathing techniques, relaxation, helpful self-talk or fan therapy) can increase their physical and psychological functioning and significantly improve their quality of life.[11,12] As well as life-changing benefits for patients, there is the financial incentive of a reduction in healthcare use including a decrease in hospital admissions and length of stay.[13]

A unique insight from respiratory trainees

Respiratory clinicians have a valuable opportunity and a central role in facilitating the patient's effective management of their breathlessness. In an attempt to develop the skills of trainees in this important task, a psychology-led workshop was incorporated into a registrar training day that was held at a north London district general hospital. Twenty trainees, with a range of seniority (specialist registrar years 3–7), participated in four 30-minute, rotating small group discussions as part of a wider training day on integrated COPD care. The challenges experienced by many trainees in talking with patients about their breathlessness were discussed and key strategies to address these challenges were explored.

There were many reasons identified by registrars for not discussing a patient's breathlessness (see Table 1 for examples). One major factor raised that is not seen within the existing literature, is the fact that it is simply difficult for doctors, even those within respiratory medicine, to talk about frightening breathlessness with their patients. Trainees explained that they frequently felt overwhelmed by the difficulties reported by patients as there was often no other medical therapy that could be offered within the appointment to diminish the patient's symptoms. Of particular concern was the inability to provide a solution to frightening breathlessness, combined with the need to cover other areas – discussing other symptoms, treatments and progress – within a single appointment led some to avoid the topic altogether. Other reasons cited included time constraints, where trainees felt that exploring breathlessness with patients had the potential to detract from other important areas that needed to be discussed. In addition, a common theme was a lack of knowledge and awareness of the available resources outside of the outpatient clinic setting, such as community respiratory teams, pulmonary rehabilitation services and primary care talking therapies. Many trainees were unsure as to whether they could access psychological support for their patients and, if so, how to go about it. Often the referral process to community or pulmonary rehabilitation teams was complicated and time-consuming. Some reported differing approaches and expectations across hospitals/departments while others cited a lack of specific training and a feeling that it is the role of a psychologist to discuss breathlessness.

Table 1. Reasons respiratory trainees find it difficult to ask about breathlessness

Perceived inability to be helpful	'Breathlessness is not a symptom I can offer an immediate solution for.'
	'I would not ask for a test if I did not know what I would do with the outcome – asking about breathlessness feels the same.'
	'It can be like opening a can of worms – I can ask the question but I don't always know what to do about the problems brought up.'
Unaware of other services	'It's often not clear what support is available for breathlessness within the wider team.'
	'Information about which resources patients can access for managing breathlessness is not always available or clear.'
	'I am uncertain of referral criteria for community programmes, for example pulmonary rehabilitation.'
	'I am unsure if other resources, like primary care talking therapy, would be useful for patients with frightening breathlessness.'
	'We don't have access to psychology to refer on to for patients struggling to manage their condition.'
Time	'Time is an issue – it is often not possible to cover breathlessness concerns in a follow-up session when other things need to be addressed.'
	'It takes up a lot of time discussing issues other than reviewing medication, and here is often not space to talk about breathlessness, which often needs a long conversation.'

Why we need to talk about breathlessness

In general, patient understanding of chronic respiratory disease is poor.[14] In the acute phase of breathlessness, the tendency exists to take a passive role and rely on clinicians to alleviate symptoms.[14,15] Clinician avoidance of particular topics creates a sense of abandonment and disillusionment within patients, whereas a good patient-clinician relationship, with mutual respect and understanding of each other's agenda, has been shown to improve adherence to treatment and encourage better self-management.[16]

Effective clinical care is a coordinated, person-centred approach tailored to the individual, carer and family.[17] Communication and understanding are central to this integrated care working. By asking about the patient's experience of breathlessness, the clinician can show an appreciation of the patient's difficulty that strengthens rapport and enables the patient to feel heard and understood. The clinician also gains essential information to enable them to tailor their input more effectively and their empathy increases patients' receptivity to key health messages discussed in the consultation.[18]

How to talk about breathlessness: a five-step guide

In response to the key messages from the trainee workshop, motivational interviewing principles were adapted by the authors to support conversations with patients about living with breathlessness (see Fig 1).

Identify the patient's hopes and goals

It is helpful to begin the consultation by understanding the patient's agenda for the meeting. The clinician can then state their own agenda, which may well overlap with that of the patient.

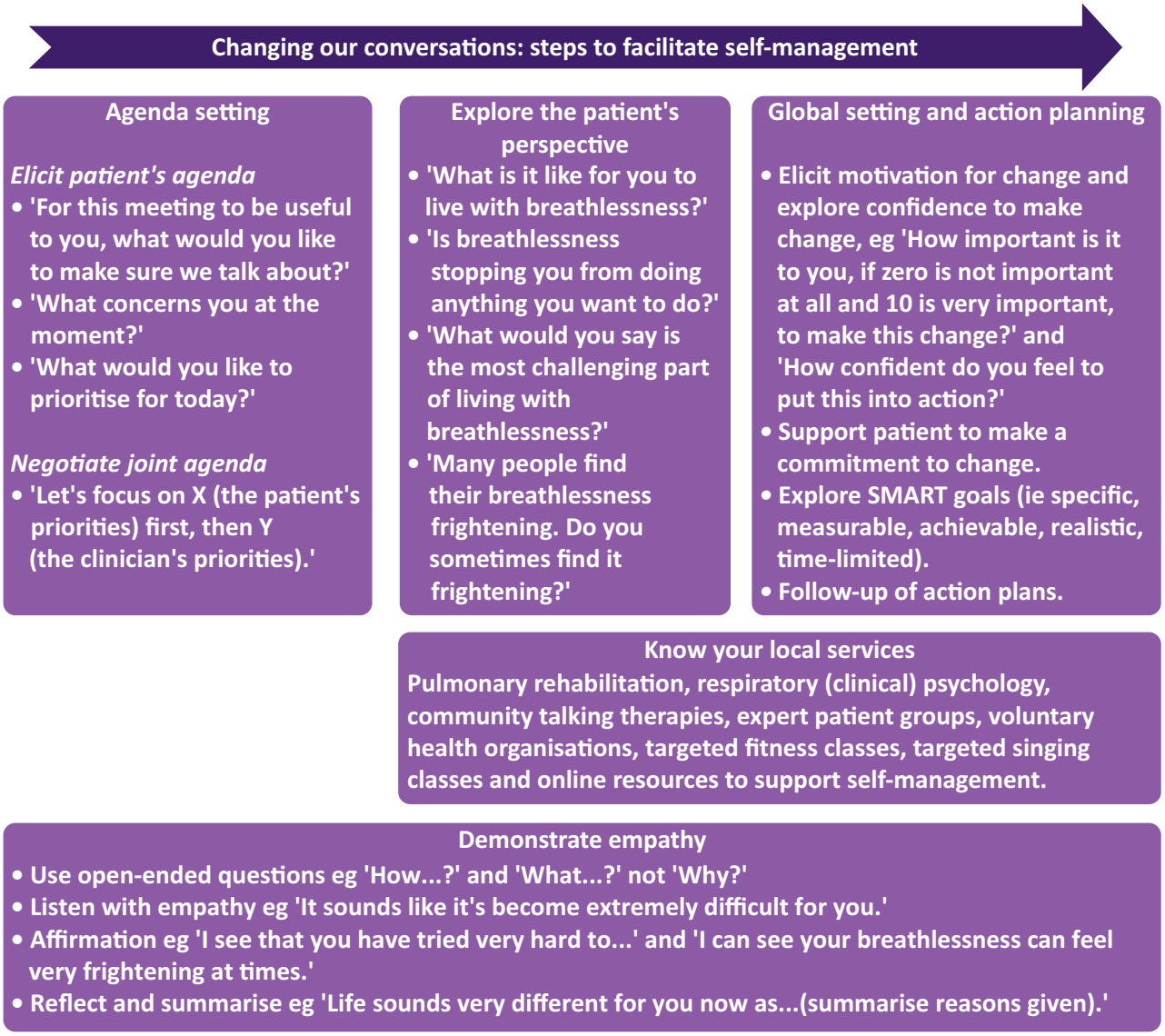

Fig 1. Steps to facilitate self-management.

This process demonstrates that the clinician supports and values the role played by the patient in their healthcare management and is the first step in facilitating a collaborative approach and supporting self-management.

While this process may take several minutes, it highlights the key topics that need discussion and also those which can be delayed or are not important to either party – thus proving time efficient for the clinician.

Understand the patient's personal narrative about breathlessness

Taking a few minutes to ask about the impact of breathlessness can transform the relevance and efficacy of the consultation. This conversation allows the patient to highlight what affects them the most and so enables the clinician to tailor their treatment approach to the patient's needs and priorities.

Accept that there is not always an answer

The simple act of listening with genuine empathy is invaluable in a healthcare context. The importance of being heard and having experiences of suffering and loss validated by a health professional cannot be underestimated. Try to shift your focus from 'fixing' to fully hearing what your patient tells you. You can then show an understanding, which validates the patient's experience and provides an essential foundation for your future work with this patient.

Know your local services

Understanding what is available and how these services are accessed will enable you to explain what options are open to a patient and help them choose the most suitable input. There are a wide range of services to support self-management of

breathlessness available across many areas nationwide. Services include pulmonary rehabilitation,[19–21] clinical psychology,[9] community talking therapies (eg Improving Access to Psychological Therapies services), expert patient groups and voluntary health organisations. There is also the option of online resources to support self-management (including the British Lung Foundation website and web-based chatrooms) especially useful for people who struggle to access what is available locally.

Change behaviour through ownership and shared decision making

Self-management of breathlessness requires confidence and a sense of personal agency to believe that one can influence one's own illness experience. Motivational interviewing strategies help the clinician to promote patient understanding and responsibility for their own health management.[22] Key principles include establishing a relationship based on mutual trust and respect; developing a partnership in which the patient's expertise, perspective and input are central to the consultation; eliciting motivation and confidence for change; and making a commitment to change with a specific plan of action.[22,23] Additional training to help the clinician guide these behaviour change conversations can be found through motivational interviewing courses (see also online learning modules eg BMJ learning module – Motivational interviewing in brief conversations).

Conclusion

It is hoped that this paper has demonstrated the value of openly exploring a patient's experience of their breathlessness. A five-step guide has been designed to show some effective ways to begin to structure these conversations. The authors and their colleagues have since gone on to identify similar challenges to talking about breathlessness within their respiratory multidisciplinary teams. As a result, interactive training sessions were held with these teams where difficulties were voiced, barriers discussed and tools for supporting more open, clinician-guided conversations about breathlessness were developed.

In conclusion, this paper has argued that breathlessness talk should not be viewed as a distraction from the 'real' work of medical input, but instead opens up opportunities for the clinician to intervene more effectively, with the patient as an active participant in their breathlessness management. It is hoped that the rationale for providing patients with a space to 'say how it is' can inspire clinicians to set aside their own fears and facilitate new dialogues across a range of healthcare contexts – with rewarding results for both clinician and patient. ■

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