Science supporting the art of medicine: improving the management of breathlessness

It is the norm for articles discussing the palliation of breathlessness to begin by restating that it is a common distressing, disabling symptom, precipitated and maintained by anxiety, difficult to palliate, and leading to isolation for patients and those caring for them. While this description is accurate, these phrases, now almost hackneyed by repetition, bear re-examination if clinicians are not to be discouraged into thinking that treatment is futile. Breathlessness is difficult to palliate but not impossible, and there has been real progress in the science of managing it and the promise of more. Pessimism should be tempered by implementation of the knowledge of what can help. The improvement in the clinical management of breathlessness of advanced disease has been led by the speciality of palliative care and re-affirms the importance of the fundamentals of the palliative care approach set out by Cicely Saunders. The usefulness of a multi-professional team working together to address psychosocial (including carer) dimensions of the symptom as well as targeting the pathophysiology of the sensation have been emphasised by the advances in basic science and translational research (neuropysiology, neuroimaging and laboratory-based psychological investigations) over the last 20 years.\(^1\) If the current knowledge were implemented by all clinicians, there could be immediate progress in improving the quality of life for patients living with breathlessness. This change would require effort and commitment rather than money and has the potential to highlight the effectiveness of palliative care in clinical and managerial constituencies with which the speciality has found it harder to engage.

Palliative care has made an acknowledged, global impact on pain control. Pain and breathlessness are usefully compared as both ‘originate in afferent nervous systems that detect and signal real or impending threats to the organism …’ and are ‘… ultimately “internal feeling” states that are most appropriately assessed by an individual’s verbal description of their own experience’.\(^2\) The speciality’s contributions to advances in pain management have primarily been in patients with cancer, and referral to palliative care services is now widely accepted in oncology. This was not true historically. It seems that the demonstrable success of palliative care clinicians in managing pain enabled the speciality to be welcomed, with its attendant practices of multi-professional working and addressing psychosocial as well as physical concerns, becoming first accepted, then integrated into oncological practice. Now, knowledge of the clinical improvements for patients with breathlessness possible when current good practice is followed need to be disseminated widely and practised assiduously.

Breathlessness is common not only in people with chronic obstructive pulmonary disease (COPD), heart failure and cancer but also in those with renal and neurological disease, specialities in which it is not yet routine to refer to palliative care, in spite of both evidence and pockets of good practice demonstrating the superiority of this approach for those with advanced disease.\(^3\) There are now a number of breathlessness services working with respiratory departments (Cambridge Breathlessness Intervention Service, Breathlessness Support Service at King’s, The Breathing Space at St Joseph’s Hospice, London, ‘Inspired’, Nova Scotia), which have led to improved access to palliative care for all patients with respiratory disease. These services work with the patient, family and referring team until there is no further improvement possible, accepting re-referral from respiratory medicine if needed or ensuring excellent continuing links with palliative care.

Transferable prescribing skills were a gateway to improvement in pain management for cancer patients; there is not yet a comparable evidence base for the pharmacological treatment of chronic breathlessness. There is also an important difference; although patients with cancer and breathlessness follow a similar trajectory to those in pain, breathless patients with many non-malignant diseases can live for years. There must be a different weighting to risk–benefit analyses when patients will need palliative medication for this length of time. Drug trials, even for those required for extended periods, generally last only weeks, more rarely months. The clinical effects of 30,000 people taking a drug for 1 year and 1000 people taking a drug for 30 years are importantly different as those with now disabling, irreversible side effects from, for example, bisphosphonates will attest. For opioids, which have the greatest evidence base in breathlessness, there is often a significant drop-out rate from trials because of adverse effects. While opioids are clearly beneficial in the end-of-life phase for those with severe breathlessness, their safety in long-term use is not yet established.\(^4\)
Information on opioid prescription from the chronic non-malignant pain literature is relevant here. There has been a move from ‘should not be denied’ in non-malignant pain to ‘use with caution’, and questions are being asked about the impact of chronic opioid use on sleep quality, oxygenation and the incidence of obstructive sleep apnoea. Clinicians also underestimate the organisational and other burdens of long-term medication. Embarking on a prescription for a drug needed daily, which gives imperfect symptom control, should be a considered decision reached only when alternative approaches have been found wanting. The other classes of drugs used routinely for breathlessness either have an absence of evidence or the certainty of problems in long-term use. A more effective pharmacological intervention for chronic long-term breathlessness would be an important advance, and antidepressants, particularly mirtazapine, show promise.

Breathlessness is recognised to be a multidimensional symptom with psychosocial as well as physical precipitants and consequences, affecting not only the sufferer but those around them. It is unsurprising, therefore, that current evidence suggests that a complex intervention using a combination of non-pharmacological and pharmacological interventions is most likely to improve the quality of life of mobile patients living with breathlessness (including carers). It seems that by making incremental changes, in a number of the facets of an individuals’ breathlessness, a clinically significant improvement can be achieved.

The evidence also suggests that it is not simply the intervention (which often itself appears to be simple) that produces a favourable change but also the way it is implemented, that is, after listening to and acknowledging patients’ concerns and considering wider solutions. Here, the analogy with pain holds; the prescription of morphine alone will not provide excellent, sustained pain control. Prescribing habits can be easily taught and are a good first step, but the larger impact comes from non-pharmacological interventions such as the attention to an individual’s needs, as an individual, in the context of their family and wider psychosocial concerns.

One possible barrier to implementation of non-pharmacological interventions is their delineation by what they are not. ‘Non-pharmacological’ is a term unlikely to inspire clinicians to ever greater heights of therapeutic success, and it makes their transferability outside the speciality problematic. A clinician being advised to use non-pharmacological interventions for breathlessness might reasonably ask ‘which non-pharmacological interventions?’, ‘what is the rationale for their use?’ and ‘Are they all equally effective?’ To this end, Spathis has been working on a classification for non-pharmacological interventions for breathlessness based on how each one primarily affects the sensation. This will facilitate both further investigation of individual facets of a complex multidimensional approach and their dissemination. Non-pharmacological interventions can be grouped as those that affect (1) Breathing, most likely to work by affecting the neurophysiological pathways, central and peripheral, involved in generating dyspnoea, for example, fan, opioids, breathing exercises and neuromuscular electrical stimulation (NMES); (2) Thinking, an intervention that targets central perception of breathlessness, such as active listening, cognitive behavioural therapy, education and relaxation techniques; and (3) Functioning, targeting mobility, for example, pacing skills, mobility aids and a personal exercise programme.

There is of course cross-over in these three groupings, and the way the intervention is offered will affect the outcome. Patients and carers participating in the evaluation of Cambridge Breathlessness Intervention Service over 10 years have consistently highlighted the value of a positive problem-solving approach. Considering, for example, the handheld fan, there is evidence that if it is simply handed to patients without explanation (thinking) of how it affects afferent signals to the respiratory centre, (breathing) or how it is best employed in shortening recovery time after exercise (functioning), encouragement to have it always to hand (thinking), how the carer may be involved by giving it to the patient when breathless (thinking), its impact will be lessened.

We can and must put some distance from the persisting nihilism and hopelessness of 20 years ago even though a ‘great ocean of truth’ remains to be discovered. We must put our energies into multi-professional and multi-speciality research, participating in research when we do not have the resources to initiate it. We can immediately implement current approaches known to help the breathless patient. Although emerging data suggest that specialist breathlessness services may offer advantages, most of the interventions for breathlessness can be implemented, without new investment and radically different training. We need rather a renewed confidence in what palliative care has always epitomised, and by demonstrating the effectiveness of interventions for breathlessness through research, we may open the gateway for a wider impact on clinical care.

References


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