

Adult domiciliary oxygen therapy: a patient's perspective

Anne E Cahill Lambert

As I recently walked around Canberra's Lake Burley Griffin in an air temperature of 5°C, I had plenty of time to contemplate the position statement on acute domiciliary oxygen therapy recently published in the Journal.¹ I have fibrosing alveolitis and am awaiting a lung transplant. I am on domiciliary oxygen therapy 24 hours a day.

There is much in the position statement to congratulate the authors on. They have rightly identified the importance for people like me of maintaining an increased level of fitness, which incorporates the use of ambulatory oxygen therapy to improve our prognosis. They have also identified contraindications for oxygen therapy, cited the appropriate levels of evidence as prescribed by the National Health and Medical Research Council, searched MEDLINE, and undoubtedly worked their way through the various committees of the Thoracic Society of Australia and New Zealand (TSANZ).

What then is missing? The patients! Perhaps I am being unfair to the authors and perhaps there is a process within the TSANZ structure whereby consumers were consulted on the position statement, but this is not immediately evident. If consumers were partners in the development of this statement, it might have been possible to address its four glaring omissions:

- The issues of access to and equity of oxygen supplies across Australia;
- Portability and comfort;
- Assessment and review; and
- Quality of life.

Access and equity

While it is well known among respiratory and thoracic physicians that not all Australians have access to free or subsidised oxygen, it is not well known in the community. Different states and territories have differing rules for patients who are on oxygen therapy. Victoria, Tasmania, South Australia and Western Australia routinely provide free oxygen, based on clinical need, irrespective of the patient's financial position. Queensland will generally provide the service if the patient is on a lung transplant waiting list, but otherwise its approach is similar to that in New South Wales, where all patients are vetted by a means test. The means test is particularly harsh, and patients must have a government Health Care Card. The Australian Capital Territory changed its rules from 1 July 2004 to bring it into line with Victoria, Tasmania, South Australia and Western Australia.

Why is it that some people in Australia have access to free or subsidised oxygen supplies and others do not? I often hear health ministers, state and federal, boasting about the wonderful universal health system we have in Australia. Everyone pays their taxes

Anne Cahill Lambert is a patient awaiting lung transplantation. She retired from her former position due to ill health. She is a lifetime non-smoker.

Lyneham, ACT.

Anne E Cahill Lambert, AM, MPubAdmin, BHA, Formerly Chief Executive Officer, Women's Hospitals Australasia and Children's Hospitals Australasia.

and their Medicare levies — yet, at the whim of a postcode, some people do not have access to a basic supply such as oxygen.

Another access and equity issue is whether the supply of oxygen is capped (ie, whether patients have access to unlimited supplies of cylinders per week or per month). While, for example, the ACT Health Minister recently explained that access would not be capped when the new system was introduced, in reality oxygen therapy is restricted by a contract. I am in the lucky position of being on a lung transplant list, and therefore my access is not capped. However, there are other (generally elderly) patients who are limited to small supplies of oxygen each month because their disease, prognosis or age precludes them from the opportunity of a lung transplant.

A further difficulty is that there are currently only three lung transplant units in Australia (in New South Wales, Victoria and Queensland). I am required to attend a lung transplant unit interstate every 6–8 weeks, as are other patients. Some ACT patients have been told that, if they travel interstate, they will not have access to the ACT government-funded oxygen supply while they are travelling or staying interstate. The limited number of lung transplant units means that the chances of patients having to travel with oxygen are quite high. Yet, because they are travelling and not resident in the state with the lung transplant unit, they are required to pay for their own oxygen.

There is surely a better way of managing all patients, irrespective of their state of residence.

Portability and comfort

The position statement mentions a range of oxygen delivery modes. The most commonly used portable cylinder in Australia is the "C" cylinder, which weighs over 4 kg when full. This is far too heavy to allow me to maintain an independent lifestyle, and I have been able to obtain CFR (carbon fibre wrap) fibreglass cylinders, which weigh less than 4 kg when full and fit neatly into a backpack. I use one when out exercising and for most of my daily life. However, even the CFR cylinder is too heavy for the long walk around the Lake, especially on chilly days. Oxygen suppliers have rentable lightweight trolleys, but these are unstable on any surface other than a smooth surface. My husband has therefore redesigned a golf buggy (I hate golf anyway) so that my cylinder can fit neatly into that. The buggy's wheel base is wide enough to allow it to cross all sorts of terrain. Stairs, however, are a problem.

What a joy it would be to all Australians needing oxygen therapy to have access to lightweight, longlasting liquid oxygen systems that weighed less than gas cylinders and did not require constant visits to oxygen suppliers for refilling.

Patients in the United States and now the United Kingdom (a new system was announced in June 2005) have access to liquid oxygen, but suppliers in Australia do not provide such a system. I am told that this is because clinicians do not want to prescribe liquid oxygen.

While the position statement gives a thorough analysis of systems available, it might have been useful if some comment were made about what patients would prefer, as the inconvenience of the accoutrements available to enhance or prolong our lives makes the whole illness process much worse than it needs to be.

Assessment and review

The position statement correctly suggests that patients should be reviewed within 1–2 months of beginning oxygen therapy, and thereafter at 12-monthly intervals. However, there is no mention of who should undertake these reviews. The logical assumption — and, indeed, good clinical practice — would be that thoracic/respiratory physicians would fulfil this role.

However, recently in the ACT I was contacted by the oxygen supplier who has the government contract and told it was time for my respiratory review, which would be undertaken by the oxygen supplier! I have to wonder at the appropriateness of such an arrangement, in view of the following:

- **Conflict of interest.** It is in the oxygen supplier's interest to increase sales of oxygen.
- **Clinical governance.** Oxygen suppliers are generally just that. They do not have a clinical governance structure in place to ensure that their ability to undertake clinical assessment is appropriate. Issues such as calibration of equipment and competence and currency of staff are also key concerns. As is privacy: I was told that my results would be passed on to the administration of my local health department, an organisation whose role does *not* include the maintenance of patient records.
- **Repetitive assessment.** All patients being prescribed oxygen are assessed by appropriate thoracic/respiratory physicians. Their lung function and other indicators are assessed at regular intervals. To incorporate another layer of review by an oxygen supplier is demeaning and disruptive to patients.

Quality of life

The authors of the position statement touch briefly on quality-of-life issues, but seem to have little understanding of what quality of life means for people dependant on oxygen therapy. Rarely does a patient wish to remain confined to barracks, tied to an oxygen concentrator. Patients' outlook on life is greatly enhanced by making some attempt to lead as normal a life as possible. In my own case, I am relatively young and it is essential that I maintain an active lifestyle to help me look after a young family and to ensure readiness for lung transplantation.

Debilitating diseases such as fibrosing alveolitis and cystic fibrosis have a huge impact on family life. Regular and uncapped supply of an extremely basic commodity like oxygen goes some way towards alleviating the stress on families and individuals in coping with the psychosocial aspects of the disease.

Issues and suggestions

One might argue that the authors were trying to provide evidence-based guidelines for the clinical aspects of oxygen therapy — that they never claimed to be doing more than that, and wouldn't presume to speak for patients or funding bodies. But is that good enough? Can the quality of life of patients (as they see it) and the appropriateness of reviews of their need for oxygen therapy really be irrelevant to their doctors?

And there are other issues. I have met people who have struggled out of their vehicles, put their cigarettes out, and wheezed their way in to the "oxygen shop" for their free oxygen because they fulfil the requirements of the means test (while others, equally or more deserving, have to wait in line to pay for theirs). Does it seem right that patients who are not committed to

improving their health outcomes should have ready access to such a scarce resource?

Perhaps it is time for some of the tobacco tax to be put into funding oxygen supplies. While cigarette smoking does not cause all of the lung disease occurring in Australia, it is responsible for a large burden of disease and death, including death from lung cancer, chronic obstructive pulmonary disease and heart disease.

It is also evident that the multilayered federal/state government arrangements for managing health care in Australia are totally inappropriate for managing something as basic as oxygen. Perhaps it is time for individual states and territories to relinquish the funds they are currently using for oxygen therapy and for the federal government to assume a management role, as they do with pharmaceuticals. This seems to me to be the only equitable way of allocating oxygen on the basis of need, rather than state of residence. Indeed, the United Kingdom has just introduced a centrally managed system for providing oxygen therapy, recognising the fragmented nature of the previous system.

In common with other patients, I will no doubt shortly become an orthopaedic surgical patient as a result of an aching back due to carting around heavy oxygen cylinders. Although I have the lighter oxygen cylinders, they become quite heavy on my back and shoulders. Perhaps it is time for physicians to start advocating for the comfort of their patients through the medical colleges or the TSANZ. A shift towards liquid oxygen systems would be welcomed by many who have lung disease and require oxygen therapy.

Surely it is also time for the medical colleges and/or the TSANZ to agree on some basic forms that physicians could use for prescribing and reviewing oxygen requirements. This would ensure that patient dignity and privacy issues were maintained.

Quality-of-life issues for patients requiring oxygen therapy should also receive more than passing attention from clinicians. I am told that there is an extremely high number of patients awaiting lung transplantation who are also taking antidepressants. This is hardly surprising, given that such patients have so much of their independent lifestyle removed so quickly. Surely this issue should also be discussed when considering how best to provide domiciliary oxygen therapy.

A final comment

Patients (or consumers, as we are sometimes called) are central to the business of illness. They know a lot about their diseases. This is not to say that some are not ill informed. However, there is a vast wealth of knowledge and experience to be tapped in having patients as partners in the development of position statements such as the recent one on domiciliary oxygen therapy.¹

The TSANZ's position statement is a good, solid, clinical paper. It could have been a great, patient-friendly statement if the views of patients had been sought and incorporated.

Competing interests

None identified.

Reference

- 1 McDonald CF, Crockett AJ, Young IH. Adult domiciliary oxygen therapy. Position statement of the Thoracic Society of Australia and New Zealand. *Med J Aust* 2005; 182: 621-626.

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