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Why Intensivists Should Participate in Home Ventilation Teams

A historical review of the birth of intensive care medicine and home mechanical ventilation; and an opinion piece on the merits of intensivists participating in home ventilation care teams.

The world is currently reeling from the ravages of COVID-19. It is still too early to know how healthcare will be transformed as a result of this epidemic. For now, it appears that COVID-19 will leave behind large numbers of survivor-victims who will need to cope with various degrees of disability. It is instructive then to look back at another pandemic that occurred seventy years ago.

Polio – Copenhagen, Kenya, London

An earlier epidemic in the 1950s – the polio epidemic – led to the naissance of intensive care medicine, and eventually the birth of home mechanical ventilation in Europe and the Americas.

Home ventilation began as a rebellion; ventilator dependent individuals wanting to leave the ICU, not to die, but to live!

In 1952, Bjorn Ibsen revolutionised the management of polio by introducing tracheostomy ventilation, with medical students performing manual ventilation in shifts. The first beneficiary was Vivi Ebert, a twelve-year old girl on the brink of death. Dr Ibsen went on to establish what is arguably the first intensive care unit in the world, in 1953, at the Kommunehospitalet, the municipal hospital of Copenhagen (Berthelsen 2003).

In 1958, Robin Cavendish, a young businessman in Kenya, contracted polio and became a “responaut.” He was transferred back to England for treatment. He survived against the expectations of his doctors and chose to leave hospital against medical advice after one year. In 1962, with his friend Professor

Teddy Hall, he developed a wheelchair with a built-in ventilator, bringing mobility to himself and other polio patients.

He lived a full and impactful life, helping to develop and market equipment that improved the lives of the disabled, and raising money together with Dr Geoffrey Spencer and others to build “The Netley Waterside House” for the recreational needs of the disabled.

Sixty years on, we can draw a few lessons from the life of Robin Cavendish. Firstly, that Intensive Care saves lives. He would not have survived and gone on to accomplish all his philanthropic deeds without the initial intensive care. Secondly, intensivists (in this case his friend Dr Geoffrey Spencer) continued to make an impact on his life, and the lives of people needing prolonged mechanical ventilation. Thirdly, and this remains true after sixty years, we make mistakes in prognostication and are often, in the name of realism and pragmatism, too nihilistic.

The Development of the CPAP Machine

Prior to the invention of the CPAP machine in 1981, patients with severe obstructive sleep apnoea received tracheostomies. The first CPAP machine was a modified paint compressor with the motor reversed! (Interview with Bron Lehrhaft - Resmedica Clinical Newsletter: Issue 14, 2011).

Many patients with neuromuscular diseases develop obstructive sleep apnoea and also may have hypoventilation during sleep. Modalities for monitoring such as continuous oximetry and transcutaneous CO₂, allow for diagnosis

and treatment of sleep disordered breathing. However, not all physicians practicing long term ventilation regularly employ sleep studies in titrating ventilatory settings.

Who Should be the Home Ventilation Physician?

If we survey the past and contemporary landscape for physicians looking after people on prolonged mechanical ventilation (PMV), we find a variety of specialties, namely – anaesthesia/intensive care (Dr Geoffrey Spencer, Dr Lawrence Duncan); neurology (Dr Augusta Alba); Physical Medicine and Rehabilitation (Dr John Bach); Respiratory Medicine/Intensive Care (Dr Nicholas Hart, Dr Joshua Benditt); Respiratory Medicine/Sleep Medicine (Dr Mark Elliott, Dr Douglas McKim, Dr Anita Simonds, Dr Jesus Gonzalez). The above list is by no means exhaustive.

Dr Mark Elliott has written a review about the necessary attributes of a physician prescribing NIV, namely – an understanding of physiology, diagnostic skills, knowledge of sleep medicine, communication skills, leadership skills, and specific education about both acute and chronic ventilation (Non-invasive ventilation: Essential requirements and clinical skills for successful practice). To this list, I would add, facility with routine and advanced tracheostomy care, including speech and swallow with tracheostomy, and facility in decannulating suitable patients. Additionally, a good grasp of the technical aspects of prolonged mechanical ventilation – the nomenclature, circuits (circle system, active circuits, passive circuits), NIV interfaces

(including mouthpiece ventilation), different modes, and how patients with different diseases and at different stages respond to various ventilatory interventions. Importantly, the chronic ventilation physician needs to be flexible and understand how ventilator users may “exploit” ventilation to help them speak louder, swallow better, even walk farther, and hence that ventilation prescription strictly to blood gases or polysomnographs is sometimes inadequate or incompletely relevant. Finally, a good grasp of the natural history of neurological and respiratory diseases, which is arguably best appreciated longitudinally by home visits, as acute wards and outpatient clinics cannot allow a complete revelation of the real baseline state.

Why Some Intensivists Should Practice Prolonged Mechanical Ventilation

If we examine all these knowledge and skill requirements, we recognise that they are not currently comprehensively taught by any one specialty, implying that chronic ventilation physicians must necessarily learn on the job, via apprenticeship with an experienced colleague if possible.

Home mechanical ventilation is an extension and fulfillment of intensive care. The intensive care unit allows the patient to survive by augmenting or replacing dysfunctional physiology using technology. Home ventilation allows the ventilator dependent patient to live at home with autonomy to express individuality, whilst providing physiological support with mechanical ventilation, delivered intermittently or continuously, invasively or non-invasively.

Should intensivists perform home visits? In the 2012 recommendation by the Canadian Agency for Drugs and Technology in Health, it is suggested that respirologists and/or hospitalists make home visits, over and above care provided by general practitioners. A recent review (Kastrup 2017) noted that one of the drawbacks in the German system is that home ventilation adjustments are made by general practitioners who are not familiar with this technology, resulting in high emergency

service personnel involvement, unnecessarily high rate of hospital admissions, and a revolving door phenomenon.

Some UK units (e.g. Northeast Assisted Ventilation Service, Newcastle; Lane Fox Unit, London) have a Clinical Nurse Specialist functioning as the main care coordinator, patient and family educator, and frontline clinical practitioner. This Clinical Nurse Specialist has to be familiar with intensive care technology, mechanical ventilation and sleep. Such a system additionally allows for scheduled and urgent visits by the consultant physician, which in their case include intensivists and pulmonologists. Such a system might arguably provide the most seamless care for patients, unnecessary acute care readmissions, since both the nurse and physician are competent and confident in the care of the complex home ventilator user - able to handle the primary disease, the respiratory insufficiency and other conditions arising.

The same Clinical Nurse Specialist-Intensivist team/couple are also invaluable, when ventilator users develop other problems that need acute hospital attention – orthopaedic injuries after a fall, acute retention of urine due to prostatic hypertrophy, per rectal bleeding due to colorectal malignancy, cerebrovascular accidents. Being a ventilator user does not magically exempt one from all these other problems. Many of these problems may need acute hospital admission, and some may need operative, endoscopic or angiographic treatment. Someone using a cuffless tracheostomy allowing leak speech may need to undergo surgery. Balancing challenges of breathing circuit leakage vs need for communication during the perioperative period would vex the unfamiliar clinician. The familiarity with acute care colleagues as well as the needs of the chronic ventilated patient makes the Clinical Nurse Specialist- Intensivist team ideally suited in coordinating or even delivering such care.

As intensivists, we are at great risk of negativity and burnout, as we only see patients in critical illness, with a significant proportion dying under our watch. When patients stabilise, they leave the unit, and unless we conduct

post-ICU rounds or manage post-critical care clinics, we really do not know what happens to them. Home visits by intensivists allow patients to benefit from the breadth and depth of our medical training, while it allows us to see both the possibilities of independent living despite various disabilities, as well as the problems that sometimes originate from our practices or our oversight in the ICU.

“I think (and communicate), therefore I am”

Did you know that people with locked-in syndrome can have a sense of humour?

“I prefer “Thermometer”; her dedication would be beyond reproach if she did not regularly forget the implement she thrusts under my armpit.” This is Jean-Dominique Bauby’s description of his bedside nurse! A former editor of *Elle*, he had suffered a massive pontine stroke, and he wrote his memoir by blinking his eyelid whilst scanning letters read by his speech therapist (Jean-Dominique Bauby: “The Diving Bell and The Butterfly”)

Do we know how to treat our critically ill patients with gentle and respectful attention?

We are rational creatures with intellect and will, what defines being human is the ability to choose, and to communicate. During critical illness, these are often lost amidst the fog of sedation or delirium. All too quickly, we reach for our trusted haloperidol or quetiapine, or restrain the patient who is restless.

Speech and communication of abstract thoughts are essential aspects of human living. When a patient is orally intubated, speech is impossible. However, not all intensivists are familiar with facilitating oral speech in the tracheostomised and ventilated patient, often settling for vague “lip-reading.” Do we not often encounter an ICU patient having a tracheostomy cuff inflated unnecessarily? How many of us know that we can alter PEEP and Ti to improve speech quality, or have actually coached a patient to vocalise? This despite clinical reports demonstrating the safety and efficacy of leak speech or speaking valve use in tracheostomised patients since the early 1990s.

“The tone of voice left no doubt that henceforth I belonged on a vegetable stall and not to the human race. France was at peace; one couldn’t shoot the bearers of bad news. Instead I would have to rely on myself if I wanted to prove that my IQ was still higher than a turnip’s” (Jean-Dominique Bauby: “The Diving Bell and the Butterfly”).

Are most intensivists familiar with both high-tech alternative and augmentative communication aids (AAC) such as eye gaze trackers? Do we know how to converse with locked-in patients using letter charts? Have we read that a fair number of patients with locked-in syndrome score their satisfaction with life at “acceptable” levels (Bruno 2011)? If not, our locked-in patients could be seen erroneously to be “as good as vegetables” to us, and we really have no moral authority to judge their quality of life and prognosis.

Patients And Families: Are We the Hosts or the Guests?

Many of our ICUs have moved towards open visitation hours. We recognise the importance of family members. However, for many of us, it is an uneasy truce. Deep down, we still yearn to be in full command. Therein lies the root of much of the angst and mistrust between patients, families and ourselves.

“In my view, we doctors are not our patients’ partners; we are guests in our patients’ lives” (Berwick 2009). Home ventilation demands that we truly honour this dimension of our profession. We do indeed learn, through home visits, that we are guests in our patients’ journey, privileged to participate and share, to help, and to grieve together.

Helping a Patient Transition From ICU

Helping a ventilator user to go home is a test of clinical acumen and teamwork. It is not something a care coordinator or junior doctor should undertake alone. The ventilator regimen, nutritional plan, medication prescription etc. should be tailored to realities at home and should be manageable by family members or caregivers. Staff in the acute hospital need to

teach patient, family members and caregivers on care-tasks. The use of audiovisual material, mannequins, electronic learning material are all necessary and helpful; but empowering patient, family members and caregivers by teaching a clinical reasoning- based approach may be more advisable than adhering to rigid checklists. Such instruction is best done by staff experienced with both poles of the patient’s care spectrum – both ICU and home.

Organ Support, Life Extension and Rehabilitation, Dying

Medicine is often portrayed as an epic struggle against our mortality. When the kidneys failed, we invented dialysis. When breathing was insufficient, the ventilator. We learnt to pace the heart, to assist the ventricles. Exoskeletons and eye gaze trackers are now realities. Expert centres worldwide are racing to develop brain-computer interfaces.

Life extension is not the be-all and end-all. Each day alive is an opportunity - to see a sunrise; to smell or touch a rose; to say “I love you” to someone; to snuggle with a dog; to read the classics; watch the latest movie or soccer match; to write a memoir; to discover the next astrophysics theorem.

When, finally, the organs cannot be supported, when suffering cannot be relieved without robbing the patient of his faculties and control, the ventilator user needs to be allowed to “go gently into the night;” the loved ones need to be supported. This is palliative medicine. This is humanity. This final step in the journey is best accompanied by the faithful and familiar intensive care cum home ventilation team.

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Conflict of Interest

None. ■

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