BRINGING CARE TO THE COMMUNITY:

A Rehab Perspective on Home-Ventilated Patients

Text and photo by Dr Valerie Ng

From the moment doctors graduate from medical school, we are bound by the Hippocratic Oath, vowing to "first, do no harm". However, we quickly learn that this is not always possible and many a time, even our best intentions are shrouded by consequences of our actions. Questions such as "what does it truly mean to treat in the patient's best interest?" or "what equates to a justifiable quality of life?" slowly ebb at our conscience as we meander through our training years of residency. Unfortunately, in-hospital training only gives you a glimpse of the patient's life without true understanding of the individual – their likes, dislikes, character and preferences, among other things.

In order to understand if such questions could be better answered by a service that knew home-ventilated patients better, I decided to do an attachment with the Home Ventilation and Respiratory Support Service (HVRSS) to further appreciate what the service entails and how it integrates into the continuity of care framework.

The power of teamwork

The HVRSS team comprises senior consultants from three main specialties – (1) respiratory and critical care medicine; (2) anaesthesiology, intensive care and pain medicine; and (3) continuing and community care. It is spearheaded by Dr Chan Yeow and supported by a team of nurse clinicians, senior staff nurses, a medical social worker and a respiratory therapist. They run a weekday, office-hours service for all home-ventilated patients across Singapore, providing care for patients afflicted with a myriad of conditions – from traumatic spinal cord injury patients in the young population, to geriatric high-functioning individuals, including ventilated patients with cancer and neurodegenerative disorders.

The HVRSS nurses form the backbone of the service. They review patients independently in the patients' homes, perform routine tracheostomy changes, monitor bloods and capillary blood gases, adjust ventilator settings and change nasogastric tubes and catheters. They also connect with the patients and their families through their genuine concern for the individuals and their welfare on top of their medical ailments. Their love and care for their patients is truly inspiring.

The beauty of community medicine lies beyond the medical care of the patient, but instead, encompasses the individual and his/her entire community as a whole. We saw a ventilated patient who suffered from Duchenne muscular dystrophy. His mother was his primary caregiver. Unfortunately, she suffered from osteoarthritis of her knees and as she became more immobile due to her knee pain, her son's care was inadvertently affected. She was unable to see a doctor due to difficulty in finding a substitute caregiver. Therefore, during one of our routine reviews with the patient, I examined her in their home and recommended some strengthening exercises and non-pharmacological treatment for her knee pains. She was extremely grateful, as this not only helped them financially but also freed up her time spent waiting in the clinic. This was when I began to see the rewards of community medicine with the HVRSS team.

From the time a patient is referred, either as an inpatient or in an outpatient setting, the HVRSS team begins building rapport with both the patient and their primary caregivers. I quickly learnt that other than the individual's own resilience, perseverance and tenacity to survive, a familial support network is integral to their quality of survival and sustainability of care. This was contrary to what I thought before – that the underlying medical condition would be the life-limiting factor. It also became apparent that a certain degree of financial capability was required to sustain decent care for home-ventilated patients in the community. In order to run the HVRSS successfully, selecting appropriate patients is one of the fundamental steps to "get right" from the start.

My rotation with the HVRSS team showed me how patients were given a new lease of life with a ventilator. We saw a young patient with a high cervical traumatic spinal cord injury. He was tracheotomised due to diaphragmatic

weakness after the accident. Being on the ventilator allows him to talk and use his laptop and gadgets with the assistance of simple aids despite being a complete tetraplegia. He has also been able to travel overseas with the assistance of the ventilator. Another success story encountered during my attachment with the HVRSS team involved an 87-year-old lady who underwent tracheostomy for prolonged intubation due to recurrent pneumonias. With the aid of the ventilator and tracheostomy, she is able to ambulate and spend her golden years at home rather than being institutionalised. This was indeed heartening for me – seeing patients, whom I had thought would not have made it past the year, functional at home and having a decent quality of life.

The many challenges

However, despites their best efforts, the HVRSS team has its limitations. My attachment with the team showed me not just the benefits of the service, but also the struggles and gaps in our society, and the ones who have "fallen through the cracks".

During one of our home visits, we saw a young patient with spinal muscle atrophy who was dependent on non-invasive ventilation overnight, dependent on all his activities of daily living and transfers but still able to mobilise independently with an electric wheelchair using the residual motor power in his right thumb and fingers to navigate and manoeuvre. It therefore struck me by surprise when he shared that he was the owner of an online marketing company and was working full-time. Yet his self-reflection of his condition and the eventuality of his future shook me the most. As his parents (who are already in their 60s) continue to age and him being an only child, there are no other substitute carers should his parents pass away or be no longer able to care for his increasing medical needs. Given their lack of financial capability to employ a helper, the eventuality of living in a nursing home with all its restrictions, coupled with loss of independence and freedom, really hit home.

The HVRSS team has always pushed the boundaries of community medicine and challenged the notion of "quality of life" as well as "when enough is enough". We had two patients with end-stage cancers on ventilators – one with thymic cancer that had metastasised to the bone, liver and lungs, and another with a recurrent rapidly enlarging glioblastoma, both with less than six months prognosis. Both were repeatedly admitted to hospital for pneumonias and other recurrent infections. This brought up the discussion of whether the ventilator was considered a life-prolonging intervention and if slowly weaning them off the ventilator as part of palliation would be ethical to relief their suffering or if that would be considered an acceleration of death. Seeing these two patients made me re-evaluate my own thoughts and understanding of the phrase "patient's best interests".

All in all, my attachment with the HVRSS team was truly an eye-opening experience for me. I am now more aware of the services available in the community and how the HVRSS team has made significant changes to people's lives. Their actions not only affect the individuals they look after, but the families and communities that are involved in their lives as well. Despite being stipulated as an office-hour service, in fact, the service goes above and beyond their call of duty; they serve not just as an accessible point of care in the community, but also as a confidante in times of need for patients and their families. As a service that traverses both the acute and community setting, they have truly embodied the meaning of continuity of care.

Legend

1. HVRSS nurse clinician assessing a caregiver's competence in putting on a non-invasive ventilation mask for the patient

Dr Ng is a third-year rehabilitation medicine senior resident at Tan Tock Seng Hospital (TTSH). As she embarks on the final leg of senior residency training, she hopes to use her specialist knowledge and expertise to further rehabilitation in the community and help TTSH set up its first ventilator rehabilitation unit.